RUNNING HEAD: HOSPICE & PALLIATIVE CARE		
Hospice and Palliative Care: What are the Preferred Communication Channels for Older Adults		
Seeking Information about End-of-Life Decision Making in Atlanta, GA?		
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I. Introduction and Objectives

The combination of an aging population, increase in chronic disease, and unstable health care system places the United States in a precarious economic and socially responsible position. As the "baby boomer" generation ages, this group will face an increase in disease burden while simultaneously living longer. These factors place the U.S. economy at risk as a result of an expected increase in health care costs if the U.S. continues to rely on a traditional medical model. An alternative medical model, one that encompasses palliative and hospice care services for individuals with chronic conditions and for those who are nearing the end of their lives, could reduce health care costs for society and improve quality of life for sick and dying individuals.

This paper will identify the importance of palliative care and hospice services in the U.S. health care system through an analysis of cost effectiveness and quality of life improvement for patients using these services. A health promotion theory focusing on the acquisition of knowledge of palliative and hospice care services for older American adults will be proposed; this theory could be used to develop a health promotion intervention in the future. To gather the data necessary to inform the selection of a health promotion theory, a research project was conducted in collaboration with The University of Georgia (UGA) doctoral candidate, Lusine Nahapetyan, and UGA College of Public Health faculty member Dr. Pamela Orpinas. This project, entitled "Planning Ahead: What Will I Do?" examined older adults' attitudes about hospice and palliative care as well as their preferences pertaining to where they would feel most comfortable obtaining information about palliative care and hospice. Data were gathered through paper and online surveys for community-dwelling seniors living in Metro Atlanta. Seniors' preferences about where they would like to obtain information on the aforementioned health care

programs was stratified based on gender and perceived health status. Many of the survey participants lived at Calvin Court, in independent-living facility for seniors in Metro Atlanta. The objectives of this research project were:

- Survey community-dwelling seniors to determine the communication channels through which they would feel most comfortable receiving information about hospice and palliative care
- Use theory to inform a health promotion program to provide seniors with information about hospice and palliative care
- Develop behavior change objectives for seniors who receive information about hospice and palliative care

II. Analysis of the Problem

Epidemiology

It is well documented that the United States' population is aging and the percentage of adults over the age of 65 is rapidly increasing. Since 1997, the US population has grown 30% and the number of individuals over age 65 has doubled (Meier, 2011). Bomba, Morrissey, and Leven (2011) reported, "By 2030, 20% of the American population, or 70 million people, will be over the age of 65" (p. 63). Simultaneously, the leading cause of death in the U.S. has changed from acute disease to chronic conditions (Meier, 2011). Healthy People 2020 indicates that over 60% of the adults in this age group will suffer from at least one chronic condition within the next 15 years (http://www.healthypeople.gov). In short, people are getting sicker and living longer (Kilinger, Howell, Zakus, and Deber, 2014).

The simultaneous increase in lifespan and chronic conditions is already taking a toll on the United States's health care system. Costs of health care are growing exponentially. Yang and Mahon (2012) noted that health care expenditures more than tripled between 1990 and 2008. Furthermore, the authors reported that although the sickest individuals make up a small percentage of the population, their health care costs are disproportionate. For example, Young and Mahon (2012) noted that "Thirty percent of Medicare's annual expenditures cover the health care costs of the 6% of people who die each year" (p. 411). These costs are frequently a result of the application of advanced and invasive technological methods of keeping patients alive.

Bomba et al. (2011) noted that "Since 75% of individuals dying each year are over the age of 65, there will be greater need for appropriate end-of-life care" (p. 63). This datum indicates a need for researchers to study whether the cost of using advanced methods to keep a dying patient alive as long as possible results in an improvement in that patient's quality of life.

Palliative care and hospice programs show increasing cost-effectiveness for the U.S. health care system and for patients with chronic conditions and terminal illnesses. The National Library of Medicine (NLM) and the National Institutes of Health (NIH) define palliative care as "treatment of the discomfort, symptoms, and stress of serious illness" (http://www.nlm.nih.gov/medlineplus/palliativecare.html). The major difference between palliative medicine and aggressive technological treatment is that palliative medicine focuses on relieving disease symptoms, rather than disease management. Palliative care emphasizes supported decision making and end-of-life care (Yang & Mahon, 2012). Mier (2011) emphasized the strengths of palliative care: "addressing symptom distress and quality of life, [multidisciplinary] care coordination, patient and family support and engagement, safety (through prevention of wrong care such as risky and unnecessary tests and procedures), and associated reductions in overuse" (p. 370). McAteer and Wellberry (2013) further emphasized palliative care's goal to relieve patient suffering through an interdisciplinary approach. The

authors noted that palliative care "can be provided whether an illness is potentially curable, chronic, or life-threatening" (p. 811).

NLM and NIH define hospice care as "end-of-life care" that includes palliative care. McAteer and Wellberry (2013) stated that hospice care is "a type of palliative care provided when curative treatment is no longer beneficial or desired, and when life expectancy is measured in months or less" (p. 811). In the United States, health insurance companies will only pay for a patient to be enrolled in a hospice program when s/he is not expected to live more than six more months. Like palliative care, hospice care provides supportive services to the patient and the patient's family in an effort to increase patient comfort and quality of life (http://www.nlm.nih.gov/medlineplus/hospicecare.html).

Proponents of palliative care and hospice argue that the aforementioned costs for aggressive health care treatment do not result in significant increases in quality of life for sick patients. Not only do patients who take advantage of palliative care and hospice programs experience lower health care costs, they also live longer than patients who use "traditional" technological health care methods. Furthermore, preliminary studies indicate that patients who choose palliative care and hospice actually experience an increase in their quality of life (Klinger et. al, 2014; Yang and Mahon, 2012). McAteer and Wellberry (2013) stated that patients who utilize hospice care show "less depression and symptom burden; feel more in control; are able to avoid risks associated with treatment and hospitalization; and have decreased costs with improved utilization of heath care resources" (p. 811).

An increase in use of palliative care and hospice would result in a direct increase in savings for Medicare. Yang and Mahon (2012) reported that if 50% of hospitals in the U.S. offered palliative care services, Medicare could save over one billion dollars annually. If more

than 50% of hospitals offered palliative and hospice care, savings could exceed six billion annually. Yang and Mahon (2012) described a 2002 study in which patient health care bills from the last five days of life were compared between patients who accessed palliative and hospice care, and those who did not. Individual members of the former group experienced health care costs that were more than \$7000 less than the costs for individual members of the latter group.

Despite enhanced quality of life and reduced health care costs, the majority of sick people in the United States do not utilize palliative and hospice care services. Klinger et al. (2014) reported that less than half of deaths in the U.S. take pace in hospice and palliative care programs. Reasons for not using palliative care and hospice services are numerous: lack of knowledge about the programs, misconceptions and misbeliefs about the programs' purposes and services, and variability in access due to geographic location. This paper will examine the barriers to access to palliative and hospice care. The paper will then focus on a health promotion theory to address the barrier of lack of knowledge about palliative care and hospice programs.

Barriers to Palliative and Hospice Care

There are three main barriers to increasing the development and subsequent patient-use of palliative care and hospice programs: barriers to acquisition of knowledge about the programs; barriers to usage by patients, including myths and misbeliefs about the programs; and barriers to service provision by health care providers.

The physician-patient relationship is an important channel by which the patient can be informed about palliative care and hospice programs, however studies find that physicians frequently refrain from giving their patients information about these programs. This could be a result of myriad factors: perhaps the physician is unsure of the patient's diagnosis or the prognosis of a disease. If a physician does not recognize that the patient has a short time left to

live, it is unlikely that s/he will recommend palliative care and/or hospice services (McAteer and Wellberry, 2013). Yang and Mahon (2012) emphasized the importance of a physician's ability to recognize "the point at which illness becomes advances or [the patient] reaches the end of life phase" (p. 412) in order to offer the patient the most comprehensive end-of-life health care options.

Approximately 80% of patients who use palliative and hospice care are over the age of 65 (Meier, 2011). McCormick (2012) advised that physicians may not be providing their patients with information about palliative and hospice care because they do not feel like they have appropriate levels of training for working with the geriatric population. Not only must a physician be knowledgeable about palliative and hospice care options, but also s/he must be able to recognize signs and symptoms of various illnesses that indicate that a patient has entered the end-of-life phase. Without both of these components, it will be unlikely that providers will be able to effectively educate and refer patients to palliative care and hospice programs.

Public misconceptions and myths are also barriers to the use of palliative care and hospice programs. McAteer and Wellbery (2013) documented confusing terminology, unclear descriptions of services provided by palliative and hospice care, and lack of information about services that are covered by health insurance companies, including Medicare, as reasons for non-use of the programs. The authors also suggested that patients who do not trust their health care providers may be less likely to investigate palliative and hospice care options, even when these programs are correctly described by their physicians; these patients may believe that their physicians are trying to coerce them into paying for extra and unneeded services. Additionally, patients and their families are frequently optimistic about treatment outcomes – even when the physician articulates a short timeline for the patient's life span. Families – and perhaps even

some physicians – want to feel like they "did everything possible" to keep their loved ones alive. Frequently this translates into using aggressive and invasive treatments that do not result in "saving" the patient's life. Use of these treatments can cause the patient's quality of life to decrease while his/her health care costs skyrocket. Another misconception about palliative care and hospice is that the programs are equivalent to "giving up" and "pulling the plug" (Yang and Mahon, 2012; Klinger et al., 2014). Education about the programs could be beneficial in dispelling myths and misbeliefs that inhibit patients from using palliative care and hospice services.

Finally, there are barriers to the actual service provision of palliative care and hospice programs. Meier (2011) argued, "An inadequate medical and nursing workforce with expertise in palliative [and hospice] care is one of the greatest barriers to access [to these programs]" (p. 356). The author suggested that the lack of providers skilled in the provision of palliative and hospice care could be amended through the implementation of evidence-based training programs, certifications, standardization of care, increased and stabilized funding streams for program development and training, and other incentives. The barrier of service provision may be especially prevalent in the southern part of the United States, where there are fewer hospitals that offer palliative care and hospice programs (Meier, 2011). In addition to a paucity of providers, another barrier to service provision is the application of culturally sensitive practices. Yang and Mahon (2012) advised that the provision of services that "are consonant with the patients' preferences, values, and needs" actually contribute to the reduction in financial costs of the health care services. This could be a result of patients forming stronger and more trusting relationships with culturally sensitive providers, which in turn increases the likelihood that the patient will pursue a treatment that is recommended by the physician.

The aforementioned barriers work in congruence to produce a lack of public knowledge about palliative care and hospice programs, which in turn contributes to a low demand for these services (Meier, 2011). Non-usage of palliative and hospice care services leads to increased health care costs over time, while usage of the programs has been shown to decrease health care costs. Additionally, patients who do not use palliative and hospice care services may experience a reduced quality of life during their end-of-life phase, compared with patients who do access these services.

III. Methods

Site and Sample

Presbyterian Homes of Georgia's (PHGA) mission is to enhance the quality of life for senior adults. Calvin Court is on of PHGA's four housing communities for senior adults. Calvin Court is an 11-story gated tower that is comprised of 241 one-bedroom and studio apartments; 250 residents age 62 and older reside in the building. The building dates to 1969 and became a subsidiary of Presbyterian Homes of Georgia in 1998. The facility is located in the Buckhead neighborhood of Metro Atlanta.

Calvin Court addresses the socioeconomic problem of lack of housing for low-income seniors by providing apartments that are subsidized by the Department of Housing and Urban Development (HUD). This means that a percentage of the building's apartments are reserved for seniors who meet certain income requirements. These seniors pay rent that is less than market-rate because the remainder of the rent is paid through HUD grants. Funding is managed by Presbyterian Homes of Georgia.

Services offered at Calvin Court include a gym and Wellness Center Director, an on site activities director, a convenience store, a beauty salon, frequent day excursions, ecumenical

services, yoga classes, and the Social Services Department. These activities operate in conjunction to create an atmosphere of support and socialization for the residents, which in turn supports Calvin Court's mission of enhancing the lives of it's residents. As an intern, I worked in the Social Services Department.

Presbyterian Homes of Georgia (PHGA) operates with nine executive staff, including President and CEO Dr. Frank H. McElroy, Jr. and Corporate Director of Human Services, Gwen Hardy. Additionally, a Board of Trustees and five Presbytery Executives govern PHGA. Calvin Court employs twelve full-time staff and several part-time staff. The full-time staff include: Administrator, Administrative Assistant/Housing Services Director, Lead Service Coordinator, Service Coordinator, Activities Director, Transportation Director, Chaplain, Wellness Director, a Maintenance Director, two Maintenance Assistants, and a Housekeeper. Full-time staff report to Calvin Court's Administrator and also to PHGA's Corporate Director of Human Services. Calvin Court employs several residents as part-time staff to work at the front check-in desk during the day. A security officer works at the front check-in desk during evening and weekend hours. Part-time staff report to Calvin Court's Administrator.

Throughout the senior-care community in Atlanta, Calvin Court is viewed as having an active staff that focuses on the best interests of the residents. The organization works with providers in the community such as Visiting Nurse Health Systems, Senior Helpers (an organization that provides assistance with transferring, ADLs, and light cleaning for Calvin Court residents), Golden Living, and Wesley Woods in order to help residents receive necessary care after medical and psychological emergencies. Significant barriers that prevent residents from accessing these services are financial and psychosocial in nature. Some of the aforementioned organizations do not accept or are not fully covered by Medicare and Medicaid;

residents may not be able to afford the full cost or even a cost-share for these programs.

Furthermore, residents may not want to receive care from the agencies with which Calvin Court collaborates. Calvin Court attempts to address these barriers by counseling residents on the importance of receiving assistance so that they can remain in independent housing, offering many options for community service providers, and referring residents to the Community Care Services Program (CCSP). CCSP provides the same services as Visiting Nurse and Senior Helpers, and also accepts Medicare and Medicaid. There are income requirements for CCSP however, which prevents some residents from being able to take advantage of the services.

Calvin Court does not discriminate in its acceptance practices for residents, which means that residents can and will be accepted regardless of "race, gender, religion, national origin, color, creed, or handicap status" (www.calvincourt.org). Furthermore, the organization employs a diverse staff composed of multiple races, ethnicities, and nationalities. While the organization houses and employs a diverse group of people, the services offered are not frequently tailored to culturally specific needs. Despite shortcomings in cultural competence, Calvin Court does work diligently to develop programs to meet the needs of diverse socioeconomic groups. These programs include providing meal tickets to residents who cannot afford to eat in the dining room, offering a food pantry for resident use, and providing transportation services for residents who cannot afford MARTA and do not qualify for MARTA Mobility.

Service Coordinators within the Social Services Department at Calvin Court work from an evidence-based perspective when helping residents and creating social service programs. For example, Service Coordinators consider theories of health care utilization when discussing health care options with clients and referring them to appropriate services. These theories also inform the language and topics the Service Coordinators may address with various residents in an

attempt to improve residents' health literacy and improve access and follow through with health and psychological care. Another example of evidence-based practice is the Service Coordinators' use of a quality-assurance professional. This individual conducts bi-monthly supervision with the Service Coordinators to ensure that the Service Coordinators are providing effective and ethical services to residents.

To gain more information about patient preferences regarding where individuals, specifically the geriatric population, would like to receive information about hospice and palliative care, research was conducted in collaboration with UGA doctoral candidate, Lusine Nahapetyan, and UGA College of Public Health faculty member, Dr. Pamela Orpinas. The research project was entitled "Planning Ahead: What Will I do?" and it's purpose was to examine seniors' attitudes about hospice and palliative care, as well as their preferred communication channels through which they would like to receive information about palliative and hospice care.

To complete this project, surveys were conducted with community-dwelling adults over the age of 65. Participants were recruited through direct contact via email and through volunteers at Calvin Court. Twenty seniors were surveyed, either through paper or online surveys. Five survey participants were men; fifteen participants were women.

Procedures

Many of the participants had vision or physical disabilities; thus, residents could elect to fill out the survey on their own or choose to have the researcher help them fill out the survey. For surveys that were conducted in-person with the researcher, the researcher read the questions to the resident and then marked whichever answer the resident verbally selected. Both the paper and online surveys were composed of the same questions. The surveys used multiple choice, yes-

no, and Likert scale questions to inquire about participants' knowledge of palliative care and hospice services, as well as their preferred communication channels for learning about palliative and hospice care. Additional details such as participants' age, religious affiliation, possession of advance directives, and perceived health status were obtained.

Measures

The main goal of "Planning Ahead" was to determine the communication channel whereby seniors prefer to obtain information about palliative care and hospice. Analyses were performed to correlate participants' gender and perceived health status with the preferred communication channel. Perceived health status was measured using a Likert scale with five choices: poor health, fair health, good health, very good health, and excellent health.

Communication channels were described by a list of eight choices, including the option for the resident to write in his/her own preference that was not on the list. The eight listed choices were: doctor or nurse; television; family; religious official; friends; social worker; Internet; and "other." Participants were permitted to select as many communication channels as they wanted.

IV. Results

The communication channels of doctor/nurse and social worker emerged as the most popular communication channels. Sixty-five percent of participants conveyed that they would like to receive information about palliative care and hospice from a doctor or nurse, and 65% of respondents indicated that they would like to receive information from a social worker. The third most popular communication channel was "family members," with 45% of respondents choosing this method.

The majority of participants rated themselves as having good health. Of the 65% of respondents who selected doctor/nurse as the preferred communication channel, 46% rated

themselves as having good health; 23% rated themselves as having very good health; 15% rated themselves as having excellent health; and fair and poor health status were each selected by 7% of the respondents. Of the 65% of respondents who selected social worker as the preferred method of communication, 46% rated themselves as having good health; 23% rated themselves as having very good health; 15% rated themselves as having excellent health; and fair and poor health status were each selected by 7% of the respondents.

Of the 65% of respondents who preferred doctor/nurse as the communication channel, 77% were women and 23% were men. Of the 65% of respondents who selected social worker as their preferred channel of communication, 69% were women and 31% were men. Among respondents whose preferred communication channel was family, the majority were men (4 out of 5 male respondents). Only five out of the fifteen female respondents selected family as a preferred method of communication.

From these analyses, it can be concluded that the majority of women preferred communication about palliative care and hospice through a social worker or doctor/nurse (9 out of 15 and 10 out of 15, respectively). The majority of men preferred communication with family members, however men did choose the communication channels of doctor/nurse and social worker as their secondary preferred channels. Because the majority of seniors prefer to obtain information about palliative care and hospice through their medical providers and social workers, it is imperative that these individuals obtain the training, resources, and skills to convey this information to their clients.

V. Analysis of the Solutions

Intervention Strategies

In an effort to help seniors gain more information about palliative and hospice care options, a health promotion intervention focusing on increasing knowledge was selected as the most appropriate option to address the research question. Bartholomew, Parcel, Kok, Gottlieb, and Fernandez (2011) advised that "Knowledge is a necessary (though not sufficient) prerequisite for other determinants, such as risk perceptions, behavioral beliefs, perceived norms, and skills" (p. 330). If an individual does not have access to knowledge about palliative and hospice care, then that individual is subsequently denied the opportunity to choose those care programs. Programs and methods to influence or increase a population's health-related knowledge can be related to health literacy. Bomba et al. (2011) advocated that "education is the first step in behavioral change and an important step in overcoming functional health illiteracy" (p. 70).

Mahmud, Olander, Eriksen, and Haglund (2013) defined health literacy as "improving people's access to health information and support capacity to use it effectively; in order for them to make informed choices, reduce health risks and increase quality of life" (p. 2). People are most receptive to the acquisition of knowledge if it is delivered through a communication channel that they perceive to be trustworthy and reliable. Thus, it can be inferred that the female participants in the "Planning Ahead" study believe that the communication channels of doctor/nurse and social worker are most trustworthy. The male participants believe that the communication channel of family to be most trustworthy.

Mahmud et al. (2013) identified the Primary Health Care (PHC) setting as the most opportune environment for improvement in health literacy. The researchers conducted a study in

Sweden whereby they developed and implemented an online communication channel in a PHC office and in a health-related community center. The researchers found that several themes emerged from their study regarding necessary elements of health communication. The necessity of empowering patients to make their own decisions based on their personal understanding of the information that was presented was paramount in helping to improve health literacy.

Additionally, tailored communication messages delivered through specifically selected communication channels (Internet, telephone, brochures, face-to-face meetings) were found to be of great importance. For example, Mahmud et al. (2013) primarily focused on the success of an online health information channel, however this type of channel would be completely ineffective for a population that is not computer savvy. The respondents in the "Planning Ahead" study did not choose "Internet" as one of their preferred communication channels. Consequently, an attempt to improve health literacy through the use of an online forum would not likely be effective for this senior population.

Bomba et al. (2011) conducted a study to address the role of health literacy in conjunction with patients' development of advance care directives that stated their preferences for end-of-life care (including the desire to participate in palliative and hospice care should they become ill in the future). These researchers advocated for the importance of social workers as communication channels. Bomba et al. (2011) noted that the lack of training on palliative and hospice care and on information communication strategies for doctors and nurses allow social workers to assume a unique role in fulfilling the communication gap between provider and patient. Essential skills of the social work profession, "such as assessment, treatment planning and interventions, including family counseling and conflict resolution, advocacy for patient and

family needs, and interdisciplinary teamwork" can enable social workers to become skilled at improving health literacy (Bomba et al., 2011, p. 74).

Bartholomew et al. (2011) recommended that health promotion planners developing interventions to influence and improve health knowledge in an effort to effect behavior change need to ask four questions to ensure appropriate program development:

Do the program materials enable the change objectives to be met? Do they deliver the intended theoretical methods and practical applications? Do the materials fit with the intended audience? Are the materials attractive, appealing, and culturally relevant? (p. 425)

As with any intervention, cultural relevance and cultural sensitivity are paramount to the success of the program. As previously mentioned, implementing an online health communication channel for the respondent population in the "Planning Ahead" study would not be culturally appropriate. These respondents indicated their preference for receiving information through face-to-face meetings with providers. Print material can be a helpful supplement to the information communicated in face-to-face meetings. If print material is used, the messages must be written in a sufficiently large-sized font in order to accommodate older patients' failing eyesight. The development of print materials will need to take into consideration reading level, ethnic relevancy, and graphic and visual attractiveness (Bartholomew et al., 2011).

Behavior Change Objectives

Using the health behavior theory of increasing knowledge, the following behavior change objectives could be used to design a health promotion intervention in the future:

- Participants will increase their ability to access information about palliative and hospice care programs.
- Participants will show an increase in understanding of services offered through palliative and hospice care.

 Participants' perceived comfort level in discussing palliative and hospice care services will increase.

VI. Conclusions

Increasing patients' knowledge of palliative and hospice care services is but one step toward increasing the development, implementation, access to, and use of palliative and hospice care services in the U.S. health care system. In order to affect the greatest impact, changes on all system levels must occur. Yang and Mahon (2012) stated, "What is urgently needed now is a concerted effort by health care systems, palliative care providers, and the government, to make comprehensive palliative [and hospice] care accessible to...ill patients and their families" (p. 415). Changes on the macro level can occur through legislation to increase funding for the development of palliative and hospice care programs. Medical colleges, universities, and professional associations can offer certificates and accreditations for providers and facilities specializing in palliative and hospice care.

In order to dispel myths and misconceptions about palliative and hospice care, Klinger et al. (2014) advised that "the existing linkage of hospice and palliative care with 'giving up hope'...[should] make way to 'conserving hope and dignity'" (p. 117). An increase in training opportunities for medical providers and social workers regarding provider-patient communication about end-of-life options could improve patient understanding of palliative and hospice care, as well as increase patient initiative to access these programs.

In conclusion, the United States' aging population is living longer while enduring an increasing symptom burden from chronic disease. This situation however, does not have to take a toll on the U.S. economy or health care system. If changes at every system level are implemented

in a timely fashion, current health care costs can be drastically decreased while patient quality of life exponentially improves.

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