Technology-enhanced Transitional Palliative Care for Family Caregivers in Rural Settings

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SPECIFIC AIMS

Family caregivers (FCGs) provide an estimated $470 billion in caregiving services annually[4]; a statistic that the United States (US) healthcare system can no longer afford to ignore. Caregiving for palliative care patients frequently requires a commitment equivalent to full-time employment, frequently causing caregiver burden, depression, and decreased coping skills and quality of life.[5,6] Often, FCGs are confronted by numerous challenges such as inadequate caregiving knowledge and skills, limited support, their own poor health, demanding family circumstances, and limited time for themselves when caring for individuals with life-limiting illnesses.[7] Although FCGs may have substantial personal health needs equal to or greater than the patients' needs,[8] the FCGs' needs have received limited attention despite the challenges they face.[9] The needs of the FCGs must be addressed in order to maintain their own health, thus allowing them to continue to provide the best care to their loved ones in the home setting, or the healthcare system will absorb the resulting costs due to emergency department visits and hospitalizations.[10-13]

Transitioning care from hospital to home, especially in rural areas,[14] is fraught with the risk of adverse events, and poor continuity of care.[15-17] Despite the fact that transitions often require extensive FCG responsibilities, little attention is paid to meeting the FCGs' needs and providing support during the transition.[18,19] It is within this realm of new responsibilities where FCGs experience not only a transition to a new palliative care approach but also the transition of care across settings and among providers. Our proposed study expands the body of knowledge regarding methods to address the needs of FCGs in transitioning palliative care from the hospital to homes in rural, medically underserved areas.

The use of health information technology (HIT) to provide healthcare at a distance has been described as the single most important way to equalize the differences between rural and urban settings.[20] Our pilot study indicated that a new model of transitional care using existing, readily available, video-visit technology is a successful way to communicate with and continue to support FCGs of palliative care patients living in rural areas.[21,22] Given these promising results and the significant needs of the FCGs in their challenging role of caring for loved ones with life-limiting illnesses, it is critically important that these preliminary findings now be examined in a clinical trial that tests extending transitional care, through the use of video visits. Moreover, reliable assessments of the monetary and time contributions of the FCGs while providing palliative care to their loved ones are lacking due to multiple challenges including the fact that such costs are difficult to obtain and need to be assessed in a prospectively designed randomized control trial to be reliable.[1,23] Therefore, the purpose of this study is to evaluate a novel, nurse-led, technology-enhanced, theory-based[24] care model of transitional palliative care (TPC) for FCGs living in rural, medically underserved areas. The TPC model for FCGs is individualized to improve continuity of care based on evidence-based transitional and palliative care principles by providing ongoing FCG support, enhancing FCGs' knowledge and skills while attending to FCGs' own health needs. We will test the efficacy of this new care model with the following **specific aims**:

Aim 1: To evaluate the effect of technology-enhanced TPC for FCGs on caregiving preparedness, communication with clinicians, and satisfaction with care for FCGs as the care recipient moves from hospital care to home. We hypothesize that FCGs randomized to the intervention will report increased preparedness for caregiving, improved communication with clinicians, and greater satisfaction with care during the study enrollment period compared to FCGs randomized to usual care.

Aim 2: To evaluate the effect of technology-enhanced TPC for FCGs' on quality of life, burden, coping skills, and depression. We hypothesize that FCGs in the intervention group will report increased quality of life and coping and decreased depression and burden during the study enrollment period compared to FCGs randomized to usual care.

Aim 3: To examine the effect of technology-enhanced TPC for FCGs on healthcare costs. Recognizing the synergy between FCGs and care recipients, we hypothesize that costs from all stakeholders (FCGs, care recipients, and health systems) of providing palliative care to care recipients in the intervention group will decrease compared to usual care. Using the Ambulatory and Home Care Record (AHCR), which is rooted in the societal perspective,[1,25] we will measure all costs of care for the FCG and care recipient, irrespective of payer.[26,27] We hypothesize that there will be a net decrease in costs for 6 months post-enrollment from a societal perspective following the addition of a TPC for FCG in the intervention group compared to the costs of care for the FCG and care recipient in the usual care group.

This revised application is responsive to **FOA PAR-16-250:** examining an innovative model of TPC for FCGs in underserved rural areas to address the public health imperative based on the rapid growth in the need for palliative care services.[28] Our study is designed to extend transitional and palliative care science to contribute to the 2016 strategic plan priority of the National Institute of Nursing Research of exploring novel approaches for effective interventions to provide compassionate support to FCGs of patients with life-limiting illnesses.

RESEARCH STRATEGY

A. SIGNIFICANCE

The AARP Public Policy Institute's recent report on family caregiving asserts that caregiving is "more complex, costly, stressful, and demanding than at any time in human history."[4] In an effort to reverse that trend, we propose a nurse-led, team-based, technology-enhanced transitional care intervention focused on family caregivers (FCGs) of rural palliative care patients. Specifically, we wish to address a significant knowledge gap regarding the needs of FCGs as they transition palliative care from the hospital to homes in rural, medically underserved areas. The proposed study is significant because it integrates three proven approaches – transitional care, palliative care, and health information technology (HIT) to meet the needs of FCGs of patients with life-limiting illnesses. The proposed study is also significant because it will address the rapidly increasing need for palliative care services and the critical need for transitional care services to medically underserved rural areas. Further, the emerging recognition of the importance of FCGs in successful care transitions and palliative care demands specific attention to their own risk for impaired health and poor quality of life, in order to minimize depression and burden experienced by FCGs.[6,29] Our proposed study addresses a significant need for FCGs as well as a significant knowledge gap for the 40 million caregivers in the United States (US),[4] particularly during transitions of care from hospital to home. **Our study will advance the science of both transitional and palliative care**.

Importance of the FCG in Effective Palliative Care

Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering in patients with serious, complex illnesses.[30] A key feature of palliative care, and of this study, is that patients, families, and care providers collaborate and communicate about care needs. Palliative care clinicians provide compassionate care to support not only patients but also their often exhausted, overwhelmed FCGs.[31,32] Compelling evidence indicates that palliative care improves patients' quality of life and satisfaction of care, while reducing pain, depression, and health services utilization,[33-35] especially with early interventions that include improving communication with clinicians and providing emotional support.[36] Indeed, a landmark study demonstrated that early palliative care not only improved metastatic lung cancer patients' quality of life and mood but also indicated better survival rates.[31,37] Furthermore, interventions that focus on the FCG to improve knowledge, confidence, and preparedness for caregiving, in turn, improve patient outcomes related to pain and control of other symptoms.[38-45] In contrast, distressed FCGs have an adverse influence on the well-being of patients with life-limiting illnesses.[46-49]

Limited Palliative Care Services

Although palliative care services are rapidly expanding, specialized practice is **still concentrated in urban medical centers.** However, evidence from emerging community-based palliative care programs demonstrates improved patient satisfaction, with patients more likely to die at home, and fewer hospitalizations and emergency department (ED) visits, resulting in lower costs of care.[50,51] Unfortunately, the introduction of palliative care services is often delayed until patients are admitted to the hospital for a medical crisis, thereby shortening the time available for patients and families to receive the full benefits of palliative care services,[9] as well as limiting the time for transition planning. Poor transitions of care continue to exist due to fragmented and silo-driven systems of care,[10,52] thus limiting transitional care across geographic distances for palliative care patients and their families, particularly those who dwell in rural areas.

Limited Transitional Care Services to Rural Settings

It is nationally recognized that **transitions across care settings are fraught with high risk for poor quality of care and adverse events**.[53-58] An effective approach to improving the quality of care and mitigating the risk is to provide continuing care across care settings by an advanced practice nurse (APN). The APN interacts directly with patients/families, both in the hospital and in the home, to promote care transitions from acute care to community-based care, assuring that continuing care needs are met.[59-64] Transitional care, defined as services designed to promote safe and timely movement of patients between levels of healthcare, healthcare practitioners and settings,[54,65] has consistently demonstrated improved quality and satisfaction with care, and reductions in hospital readmissions and healthcare costs.[66,67] This direct service care delivery model is not viable, however, for patients and FCGs, discharged from urban medical centers who return to their homes in distant, rural locations. Further, there is a **marked absence of transitional care models that address the needs of rural palliative care patients and FCGs who transition care from the hospital to home.**

The combination of limited palliative and transitional care resources **results in limited transitional palliative care (TPC) available to persons** with serious, life-limiting illnesses **living in rural areas.** Patients travel to urban areas for treatment and nurses travel from an urban medical center to patients' rural homes – both are burdensome in terms of time and cost, making the provision and evaluation of transitioning health services to palliative care in rural settings of critical importance.[68,69] In addition, there is a disproportionate and growing population of older adults in rural communities. For example, in Minnesota, 30% of the state's residents live in rural communities, yet 41% of rural residents are over age 65, which has significant implications for healthcare services.[70] The use of HIT may help fill this gap.

Health Information Technology

Defined as the use of technology and communication systems to provide healthcare at a distance, HIT has developed with the advance of information and telecommunications resulting in **easier to use technologies with lower costs.**[71] Furthermore, HIT-focused healthcare system redesign is transforming the delivery of care for patients with serious health conditions,[72] resulting in improved outcomes and decreased healthcare utilization.[73] Supporting rural healthcare for decades,[74,75] HIT has been used to inform, educate, and support FCGs to improve knowledge, competence, and overall ability to care for their loved ones through web- and telephone-based telemetry/remote monitoring.[76,77] Video technology has been used to enhance case management interventions such as health education, medication management, assessment, and monitoring at lower costs than traditional home delivered services, although evaluation of the effectiveness of care delivered to the home via interactive video is limited.[78,79] Direct-to-consumer use of video conferencing HIT is relatively new[80] and, unfortunately, **current transitional care models do not use video interactions** to directly connect the clinician to the patient and FCG at home – relying instead on person-to-person and telephone interactions. Optimizing the use of HIT requires the development of models of care that capitalize on clinicians' strengths, patients' and families' capabilities, and the features of the technology.[81] Indeed, the **benefits of video conferencing** add dimensions to caring through access to visual cues that result in increased patient/family and nurse rapport and increased knowledge and social support.[82-85] The proposed study extends direct-to-consumer video conferencing within a novel care model that includes transitional care to FCGs and their care recipients with life limiting illnesses living in rural areas.

Importance of the Family Caregiver in Effective Care Transitions

The importance of FCGs in transitioning patient care across settings cannot be overstated. Individuals most at risk for hospital readmission or ED visits are often too sick or cognitively impaired to self-manage their care.[86] Hence, the FCGs play an instrumental role in ensuring the successful implementation of the care recipient's post-acute plans of care by assisting in symptom control through managing medications, coordinating follow-up visits, and anticipating and sequencing care.[18,87] Recognizing the critical contribution of FCGs requires that their needs be addressed separately from the patients' needs and included in a plan of care.[88] Although the importance of FCGs for palliative care patients is well-documented,[41,89-91] interventions focused on FCGs in transitional care models are limited.[18,87,92,93] Moreover, the financial contributions of the FCGs in general, and FCGs in the transitional care setting in particular, have not been comprehensively evaluated.[1] Evidence documents that FCGs need more education to develop the requisite knowledge and skills, including optimal communication with clinicians, advance care planning, preparation for caregiving, and personal support.[94] A recent addition to the Project RED (Re-Engineered Discharge) highlights an important facet of FCGs in the transition period – that of integrating the unique needs of FCGs into the discharge planning for the patient.[86]

Summary

This study proposes a novel technology-enhanced video intervention to support FCGs in the transition of their loved ones from hospital to home, based on FCGs' unique needs **rather than as an adjunct to patients' needs**. Although palliative care principles promote the unit of care to be the patient and family,[28,95] the emerging literature, recognizing the profound physical, emotional, social, and financial impact of caring for a loved one with a life-limiting illness in the home environment, has led to a call for increased support for the FCG transition experience.[96] Our proposed care model draws from existing strategies shown to positively influence FCG outcomes in home-based palliative care practices,[7,8,89,94,97-105] caregivers of patients with cancer,[9,41,90,106-108] and transitional care models, and forms in a new way the basis of the experimental intervention.[18,86,87] Few, if any, studies **have utilized HIT (video visits) in a transitional care model to address the needs of rural FCGs of palliative care patients as they transition from urban medical centers to their homes in underserved areas; nor have they evaluated the net savings in cost from a societal perspective. Coded data will be shared with Duke University.**

INNOVATION

National experts have called for developing strategies for transitional care for new populations such as FCGs of palliative care patients.[109,110] The proposed research is innovative because it represents a substantive departure from current transitional care approaches that are limited to in-person interactions between a clinician and patient in both the hospital and home. Our care model advances an individualized approach to extending palliative care and provides transitional support for families in rural, underserved areas using HIT. The proposed study is the first known study to do so.

The use of HIT in community-based settings such as homecare and hospice have been well received by patients, family members (especially FCGs), and clinicians.[83,84,111-115] We will make use of video visits as a unique means to facilitate TPC across settings. This use of HIT and communication systems to provide healthcare at a distance has developed with the advance of information and telecommunications, resulting in lower costs and easier to use technologies,[71] and has been described as the single most important way to equalize the differences in resource availability between rural and urban areas.[20]

Another innovation of this application is the comprehensive assessment of the true financial burden borne by FCGs – a topic that has been recognized as a critical gap in the literature.[1] We will measure utilization and costs associated with TPC from a societal perspective, which will capture costs borne by the FCG, patient, employer, and health system irrespective of payers.[1,25] Therefore, our study will help define the value, types, and sources of resources used in providing palliative care, including the out-of-pocket costs for medications, supplies, care providers, travel expenses, and forgone time (time costs) for FCGs.[1,25,116]

Potential Impact

Rural America comprises over 97% of the total US land mass and contains approximately a quarter of the total US population.[117] The findings from our proposed study will advance TPC strategies for FCGs of rural palliative care patients, and provide evidence of an effective care model to support continuity of in-home care for the FCGs of patients with life-limiting conditions. It is expected that providing TPC for FCGs of palliative care patients in underserved, rural areas will result in similar outcomes that already exist with TPC approaches in urban areas, including increased patient satisfaction, improved health outcomes, and lower healthcare costs. Further, the proposed study addresses three independent yet inter-related healthcare foci: transitional care, the needs of rural FCGs, and the rapidly growing field of palliative care. Our study will not only address the critical barrier imposed by distance, but also **extend palliative care practice** by improving transition management for the impending dramatic increase in the numbers of FCGs of seriously ill patients in rural areas through evolving demographic shifts.[70] By focusing on care transitions for FCGs of palliative care patients and enhancing those transitions with the use of HIT, we aim to improve the transition care experience for FCGs (i.e., reduce caregiving burden, improve FCG physical and mental health, improve FCG management of care recipient symptoms) and subsequently decrease healthcare utilization and costs. Lastly, the proposed comprehensive cost assessment will help inform the healthcare community of the true financial burden borne by FCGs, which may, in turn, help FCGs plan and be prepared for the financial commitment they will likely undertake while providing care to their loved ones. More broadly, this study will inform health policy that recognizes and ideally supports the financial impact of caregiving on FCGs who provide a substantial portion of palliative care. If the proposed intervention (TPC for FCGs) is proven successful, knowledge about cost impact of the intervention will be crucial to scaling up the intervention.

B. APPROACH

Preliminary Studies

Study #1. We examined the feasibility of using existing HIT to provide older, healthy individuals at home in rural areas with a means of regularly engaging with a nurse across distances.[21] Video visits between the patient and the nurse were conducted using a 3G-enabled Apple iPad, a cellular phone data service, and a web-based, HIPAA-compliant video conference service. Participants and clinicians reported the technology as useful and easy to use. Standard observations revealed the importance of the visual cues provided by the technology to enhance communication, engagement with the clinician, and satisfaction with video visits.[21] Findings from this study validated our hypothesis of the feasibility of older adults living in rural areas using a simple and readily available technology intervention, when training and technological support was provided.

Study #2. In a pilot test of a technology-enhanced intervention with palliative care patients and their family caregivers living in rural areas, we learned that the problems for care recipients and FCGs pertained to health-related behaviors, as well as physiological, psychosocial and environmental issues. We learned that patients introduced to palliative care while hospitalized, usually for a medical crisis, were late in their disease trajectory and often experienced deteriorating cognition that interfered with participation and self-reported data collection over time.[22] However, their FCGs remained very committed to the technology-enhanced TPC intervention and wanted to continue in the study even though the patient could not participate (or after the 2-month intervention period ended). As their loved one transitioned from hospital to home, FCGs reported that the nurse-led video visits provided continuity of care and assistance with care coordination that was otherwise not available. The FCGs in the control group reported a less coordinated transitional care experience.[22] The majority of ED visits during the pilot study were due to symptom exacerbations for which the FCG was not prepared. Findings from this study prompted us to now include anticipatory guidance, such as FCG Readiness Plans, individualized information and education, to proactively prepare and assist the FCGs in managing symptom exacerbations at home.[2] No patient/FCG in the intervention group was lost to follow-up due to issues with using the technology, as we were able to immediately remedy any technological issues with the equipment or connection. Findings from this study substantiate the intervention in the proposed randomized controlled trial (RCT), as we now include information, education, support, and advocacy to the FCG that will improve their overall well-being and ability to care for their loved one at home.

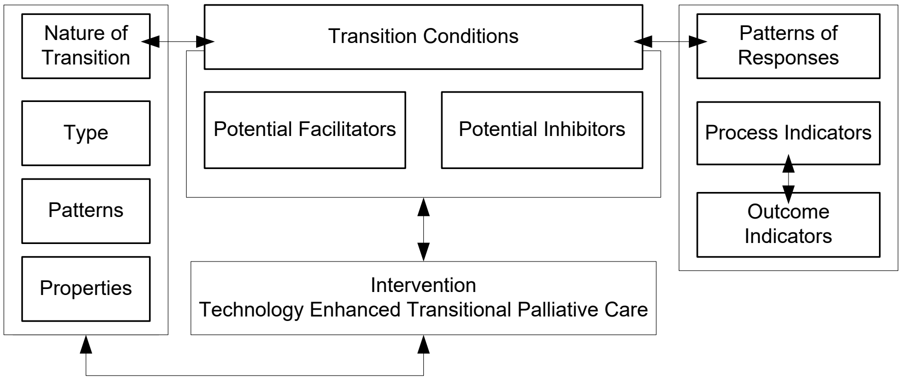
Summary. Our preliminary work provides the foundation on which the research team will successfully complete the proposed study. In preliminary study #1 the investigators determined the resource allocation and support necessary for successful video visits. Results from preliminary study #2 documented the extent of the practical value of the technology-enhanced TPC intervention and the need to intentionally focus on supporting FCGs during the transition period. We have addressed this in our proposed RCT by utilizing a novel, nurse-led, technology-enhanced, theory-based TPC care model focused on FCGs. The proposed study is the next logical step to test the effect of our novel model of care to support FCGs of patients with life-limiting illnesses.

Theoretical Framework

Transitions are defined as changes due to illness, development and lifespan, or due to social reasons, such as family caregiving.[118] Transition theory[24] provides a framework by which to understand the complex adaptations made by FCGs as they manage the changes associated with caring for a family member new to palliative care and recently discharged from the hospital. Transition Theory has been **used extensively to provide the theoretical foundation for other studies of FCGs** of persons with cancer and other chronic conditions.[119-123]

Transitions are complex, multidimensional processes that create vulnerability in an individual. Several transitions may occur simultaneously. Depending on the response to the transition process, the health and well-being of the individual can be enhanced or diminished. Transitions are affected by personal, community, and/or social conditions – all of which can serve as potential facilitators or inhibitors (barriers) to a successful transition. Outcomes of the transition are identified by the individuals' patterns of responses including the transition process and outcome indicators (Figure 1).

Figure 1: Transition experiences among family caregivers of palliative care patients



In our proposed study, the nature of the framework involves two salient types of transition: (1) the care recipient's eligibility for, and acceptance of, palliative care due to a life-limiting illness and (2) the transition of the care recipient from the hospital to home. Both of these types of transition have complex patterns. Transition properties include the quality of the FCG-care recipient relationship. Also, caregiving demands during the transition may influence the transition condition. Personal, social, and community transitions can act as either facilitators or barriers. For instance, FCG beliefs about caregiving can have a positive (facilitator) or negative (barrier) impact on caregiver well-being.[124-127] Conditions of the transition (as facilitators or inhibitors/barriers) include spiritual/religious beliefs,[128] time available for caregiving (other FCG responsibilities & demands),[129] decision-making preference,[130] health literacy,[131] income, FCG support needs,[132] readiness for hospital discharge,[133] and FCG personal health issues.[129]

In this study the FCG transition process indicators will be measured by FCGs' preparedness for caregiving,[134] communication skills,[135] and satisfaction with care (Aim 1).[136,137] Recognizing the potential effect of caregiving on FCGs' health, we will measure FCGs' quality of life,[9,138] coping,[139] depression,[140] and burden[141] as transition outcome indicators (Aim 2). The FCGs have a substantial effect on care recipients' overall care and symptom management; therefore, we will in turn evaluate healthcare costs from a societal perspective including costs borne by FCGs and care recipients (Aim 3).[8,87]

Research Design

The RCT design will be used to test the efficacy of technology-enhanced TPC for FCGs on outcomes related to the FCGs' experience and determine the impact on costs from a societal perspective. After informed consent is obtained, FCGs will be randomly assigned to one of two groups by computer-generated randomization lists: 1) the experimental group or 2) a "usual care" or control group. Consistent with transitional care models,[142,143] the intervention period will continue for 8 weeks after care recipients are discharged from the hospital.

Setting

The setting for this study is the Mayo Clinic Hospitals in Rochester and Mankato Minnesota and LaCrosse Wisconsin. While patients at the Mayo Clinic Rochester Hospital comr from all regions of the US and many forgein countries, the majority (80%) come from within a 120-mile radius of Rochester. The same holds true for the more community-based hospitals in Mankato and

LaCrosse. Of the 31 counties in the major catchment area of the clinic, 26 are designated as rural or federally designated medically underserved areas.[144,145]

The Palliative Care consulting service is available to any patient hospitalized at Mayo Clinic Hospital — Rochester, Mayo Clinic Health Sytems in Mankato and/or LaCrosse. The Mayo Clinic Rochester service is organized into 3 teams. Each team has a physician and an advanced practice clinician, plus students. On average there are 6-10 new consults per day. The palliative care teams meet daily to discuss new and continuing patients. Dr. [redacted] (Co-I), [redacted] [redacted] (pharmacist), [redacted] (SW) and [redacted], (APN) are members of the palliative care consulting service and members of our research team.

The Palliative Care consulting service in the Mayo Clinic Health System hospitals in Mankato and /or LaCrosse is smaller and includes one team for each site. The research coordinator will work independently of the Palliative care clinic team at these hospitals.

Sample – Target population

Our target population is community-dwelling adult FCGs providing care to a loved one who has a serious life-limiting condition and is new to palliative care, the care recipient will also be consented into the study. A FCG is broadly-defined as the person self-identified as the family member or unpaid friend who is the primary informal caregiver for a patient with a terminal illness. The FCG may or may not be a member of the care recipient's nuclear family. FCGs and their corresponding care recipient will be approached for study enrollment by either members of the palliative care team or the study coordinator (SC) using an IRB-approved informational brochure, including contact information for members of the study team if further discussion is requested, during the care recipients' hospital stays. Alternatively, the study coordinator may call a patient's primary caregiver to introduce the study if the caregiver and the patient meet the criteria for enrollment. Interpreters will be available for individuals who have difficulty with the English language.

FCGs

Inclusion Criteria. Any adult FCG (≥21 years of age) of adult patients (≥21 years of age) hospitalized at Mayo Clinic Hospital — Rochester, Mayo Clinic Health Systems in Mankato and/or LaCrosse who receives an in-hospital palliative care consult and lives in a Minnesota, Iowa or Wisconsin county that is designated as medically underserved or rural will be invited to participate.

Exclusion Criteria. The FCGs of patients who live in Rochester, MN, will be excluded. Rochester, MN is not considered a medically underserved or rural area.[144,145] The FCGs of patients with left ventricular assistive devices, documented chronic pain, use of home infusion pain pumps, or documented active addictive behaviors (documentation of FCG's current substance use or treatment in care recipient medical record) will be excluded from this study because of their unique needs in caregiving are not addressed by this study.

Care Recipients

Inclusion Criteria. Any adult patient (≥21 years of age) hospitalized at Mayo Clinic Hospital — Rochester, Mayo Clinic Health Systems in Mankato and/or LaCrossewho receives an in-hospital palliative care consult and lives in Minnesota, Iowa or Wisconsin will be invited to participate.

Exclusion Criteria. Patients with left ventricular assistive devices, documented chronic pain, use of home infusion pain pumps, or documented active addictive behaviors (documentation of current substance use or current hospitalization for substance use in medical record) will be excluded from this study because of the unique needs of their FCGs are not addressed by this study.

Recruitment. Eligible FCGs and care recipients will be introduced to the study by a trained SC over the phone or in person using an approved detailed phone script. Due to COVID-19 hospital visitation restrictions, we will not rely on members of the hospital palliative care consulting team to introduce the study with potential caregiver participants during consultations with the care recipient. A study coordinator may meet with the palliative care teams as needed or call palliative care team members o ascertain potential recruits.

Our target population is community-dwelling adult FCGs providing care to a loved one who has a serious life-limiting condition and receives a palliative care consult. However, we will also consent the care recipient Informed consent of the hospitalized care recipient will be obtained by a trained SC in person via written informed consent or via Ptrax Docu Sign, over the phone (verbally) or email of electronic consent following a conversation outlining the risks, benefits and goals of the investigation. The SC will allow ample time for this conversation, which will include the care recipient's understanding that the study involves collection of data from their electronic health record, discussion of their symptoms with their FCG, and collaboration between their FCG and their primary care provider/specialty providers related to goals of care.

Enrollment. The study coordinator will either visit in person or call the FCGs and care recipients prior to the care recipients being discharged, to further explain the study, obtain written consent in person and/or via Ptrax DocuSign or email electronic consent and, if possible, collect baseline data.

If a care recipient lacks the cognitive capacity to provide consent based on an IRB-approved assessment of their understanding of the study, the care recipients' documented legal authorized representative will sign or verbally the consent (see above) form on their behalf. We will then document assent of the care recipient on a separate assent form.

Upon completion of the informed consent process, the SC will retain documentation of the FCG's consent and the care recipient's consent/assent along with the assessment in the research study files, including the name and job title of the study team member who explained the study, a brief description of what was explained, questions (if any) that were asked and answered, confirmation that the subject expressed understanding of the study and willingness to participate, and the list of written information given to the subject.

Based on recruitment approaches, including introduction of the study by our trained SC and, when possible, by the members of the hospital palliative care consulting service, review of palliative care admission lists by a study coordinator, FCG remuneration, our prior experience enrolling hospice eligible patients while still hospitalized,[146] and flexibility in data collection to meet FCG preferences, we are confident in our ability to recruit the necessary 8 participants per month to meet the subject accrual goals in a timely manner.

Sample Size and Power Calculations

Determination of sample size is based on the analyses of study Aims 1 and 2 to detect a meaningful effect size. The focus of this study is FCGs. With a sample size of 100 FCGs per group, we will have 80% power to detect an effect size 0.487 at an alpha level of 0.01, assuming a two-sided, two-sample t-test is appropriate. This suggests that if a standard deviation of difference between two groups for a particular endpoint is 1 unit, then a difference of 0.487 points per month between two groups for that endpoint will be detectable with this sample size. Given that our primary outcome of interest is rate of change, only FCGs with at least one post-baseline measurement would be able to be evaluated. To account for a possible attrition rate of ~30%,[9] due to unanticipated events such as loss to follow-up, we plan to recruit a total of 500 FCGs per group at an average of 8 FCGs per month over a planned 36-month enrollment period. We are confident we will enroll the target number of FCGs, as there were over 300 patients seen by the palliative care consulting service in both 2014 and in 2015 and discharged home to the major catchment area of the study setting.

The sample size of 100 FCGs per group will have approximately 87% and 75% power to detect a 20% difference in hospitalization and ED visits, respectively. This power calculation is based on a mean number of hospitalizations of 0.75 (SD=0.4), and mean number of ED visits of 0.45 (SD=0.2), using a 5% level two-sided, two-sample means t-test,[147,148] and assumes monthly healthcare costs of $2,000 for the intervention and control cohorts for a common standard deviation of $1000.

Figure 2.Technology-Enhanced Transitional Palliative Care for Family Caregivers

Intervention Objectives

Caregiving in Palliative Care[103,108]	**Caregiving in Transitional Care**[18,143,149]
1. Education on palliative care 2. Self-care for the caregiver a. Balancing family, self, and caregiving responsibilities b. Sleep and rest c. Accepting help 3. Education on role of caregiver in palliative care context 4. Strategies to respond to care recipient physical symptoms and emotional issues 5. Goal setting and problem solving 6. Advance care planning	1. Education regarding care recipient medications, administration, and side effects 2. Discuss importance of follow-up with primary care, specialty providers 3. Education regarding indications of changes in care recipient condition and how to respond 4. Follow-up visit/Reconnect to primary care provider 5. Integrated care plan with health & community services 6. Communicating with healthcare providers

Timeframe of Activities

	Post-Discharge/Community based Visits	
Each Hospital Day	Weeks 1-4	Weeks 5-8
APN daily interaction including transition planning with FCG	Minimum of 2 virtual visits/week by APN with FCG, phone calls as needed	Minimum of 1 virtual visit/week by APN with FCG, phone calls as needed

We will also recruit a total of 500 corresponding care recipients per group.

Experimental Group: Technology-enhanced transitional palliative care intervention.

An intensive 8-week TPC intervention for FCGs is focused on the needs of FCGs of palliative care patients. Study enrollment will occur during the care recipients' hospitalization when a palliative care consult first occurs. The intervention includes dual pre-discharge and in-home components. Because only those FCGs who live outside of Rochester will be included in this study, the in-home component will be conducted using video visits. The TPC for FCG incorporates key objectives of both palliative and transitional care to be achieved during the intervention period as described below, outlined in Figure 2, and detailed in Appendix A.

There are no intervention activities planned for care recipients.

A study nurse will develop an individualized FCG plan of care based on their assessment of FCG risks, needs, strengths, and preferences.[150] A unique plan of care to support FCGs includes: (1) a wellness plan to meet their own self-care (preventive and health-related physical and emotional wellness needs) and concerns during the transition period and (2) help for the FCG to meet the care recipient's needs. FCG Readiness Plans are key components of the FCG plan of care providing anticipatory guidance to address self-care needs and to meet common symptom management challenges for use by FCGs. The nurse will assist the FCG in implementing the plan of care and refine the plan of care to accommodate changing caregiving needs throughout the 8-week intervention through FCG advocacy, teaching, guidance, and counseling through in-person visits (during the hospital stay), and video visits and phone contacts at home. A copy of the individualized self-care plan will be provided to the FCG at the end of the intervention. Dr. Dose (Co-I) contributes the necessary expertise to oversee and train the study nurses in the TPC for FCGs intervention.

The TPC for FCG intervention will be provided by experienced, certified palliative care registered nurses. Review and recommendations of plans of care will be provided weekly and more often as needed by a study palliative care team (physician, pharmacist and social worker). Team meetings will focus collectively on identifying and meeting the unique caregiving and self-care needs of each FCG incorporating tenets of both transitional care and palliative care (Figure 2). Review and updates of the plans of care will be conducted with the FCG and other clinicians on the study team to meet mutually agreed and attainable goals.

Part 1: Pre-discharge intervention. The study nurse will make the first pre-discharge I visit with the FCG within 24 hours of study enrollment either in person or via video and every other day visits with the FCG during the remainder of the care recipient's hospital stay. The study nurse will have access to all baseline data collected to assist with assessment and care planning (See Table 1 below for variables and measures). During the pre-discharge visits the nurse will: (1) assess the FCG's physical and emotional self-care needs, including the involvement of secondary caregivers and/or formal service providers to support the FCG and develop a FCG wellness plan; (2) assess the FCG's knowledge and skills for skillful caregiving; (3) begin transitional care planning by working with the FCG, the palliative care consulting service and acute care staff, and local community service providers; and (4) develop individualized FCG Readiness Plans (adapted from Hospice & Palliative Nurses Association and AARP materials)[2,117] to anticipate caregiving needs that may arise when they return home. On the day of care recipient's discharge, the nurse will confirm the FCG's understanding of caregiving needs, physical and emotional readiness for caregiving, and confirm that plans for FCG self-care and respite are in place.

Part 2: At home technology-enhanced intervention. A minimum of weekly video visits will occur during Part 2 of the study. The first video visit by the nurse with the FCG will occur within 24-48 hours of hospital discharge. During visits the nurse will: (1) Provide ongoing education, guidance, and support to the FCG to develop self-care and caregiving skills; (2) Coordinate the implementation of the community-based aspects of the transitional care plan to address the FCG's as well as the patient's needs; (3) reaffirm and provide education and anticipatory guidance for the use of individualized FCG Readiness Plans for common care recipient symptoms such as pain, breathlessness, anxiety, etc.; (4) if requested, collaborate through active dialog with the local community resources included in the transition plan; (5) if requested, collaborate with the primary care provider/specialty providers related to goals of care; (6) coach the FCG in preparation for care recipient/provider office visits; and based on her continuing assessments; and (7) provide additional video visits/phone calls to support the FCG. Palliative and transitional care intervention objectives and activities are listed in Figure 2. Frequency type and length of contacts will be documented to quantify the dose effect of the intervention.

Video visits will be accomplished via the Zoom application using the equipment of choice by the FCG: a 3G-enabled iPad (provided by the study) or their own Smartphone or personal computer enabled with a camera for video visits. Any required training on the equipment and software will be conducted by the study coordinator in person or over the phone during Part 1 of the intervention with additional 24/7 technical support provided by the study coordinator and the IT solutions contractor (Caryl Technologies, LLC) during Part 2.

The intervention will continue for the FCGs during the 8-week period. Based on our prior experience with the FCG population, it is possible that the care recipient may be placed in a long-term nursing facility or die during the 8-week study period. In the case of the death of the care recipient, bereavement support (phone calls, video visits, and written educational materials) for the FCG will be provided for the duration of the 8-week intervention interval.

Control group: Usual care condition

The FCGs randomized to the control group will receive a phone call by a member of the study team reminding them of the study and the next scheduled data collection date. This call will account for the nonspecific conditions of expectancy, social support, and attention considered necessary to generate placebo effects.[151] If concerns are identified during the attention control interaction between FCGs and study personnel, the FCGs will be advised to call their primary care provider. Control group care recipients will receive consult visits by the palliative care team while hospitalized, usual hospital discharge planning, and primary and specialty care in the community after hospital discharge. Services received by the FCGs will be collated and considered for analysis as confounding factors. We do not anticipate care recipients will participate in any study activities.

Study procedures

Study Preparation and Monitoring. Following IRB approval, the study coordinators and clinician members of the research team will be educated on the purpose of this study, as well as trained in all study procedures by the investigators; training will occur at study initiation and at subsequent quarterly reviews of study procedures.

Intervention Fidelity. The investigators will ensure that all study personnel are delivering the intervention according to the study procedure manual through weekly supervision/monitoring during the first month and monthly thereafter. We will ask caregivers if we can record their video visit for fidelity monitoring purposes, The information would stay internal and the caregivers would be given the opportunity to decline being recorded. An intervention guide will be developed to help assure fidelity to the protocol. To guarantee intervention fidelity, Investigators will audit the first 6 intervention interactions and evaluate with a detailed checklist; 100% adherence is the expectation. Any inconsistencies or deviations from the protocol will be addressed with the study team immediately. To monitor fidelity over the course of the study, Drs. Griffin, Dr. Holland and Dr. Vanderboom will use a check list to audit at least two intervention interactions for each FCG per study quarter. Challenges to intervention fidelity and how they will be resolved will be discussed with the intervention nurses during quarterly meetings. Review of study procedures and retraining of the intervention nurses and on-call palliative care staff will be done by the investigators, as needed.

Scientific Rigor and Transparency. Attention to scientific rigor and transparency is demonstrated by our plan to use methods to minimize bias and limit threats to internal and external validity. We will accomplish this by using the following: (1) a theoretical framework to guide development of the intervention; (2) validated measures specifically designed to evaluate caregiving and palliative care outcomes; (3) a clear and reproducible description of the intervention components and approach; (4) clearly outlined methods to evaluate fidelity to the intervention; (5) plans for exploring retention of participants during the intervention and data collection phase and determining factors that promote and/or hinder ongoing study participation; and (6) an inclusive sample to produce results that can be generalized to men and women.

Authentication of key biological and/or chemical resources. Findings regarding sex differences in FCG outcomes [9,152] have not been reported, although the majority of FCGs are female.[153] Based on the unequal sex distributions in other studies of FCGs,[154-156] we anticipate the enrollment of FCG female participants will be greater than males. We have no evidence to suggest that the sex distribution of FCGs will impact our outcomes.

Variables and Their Measurements

Copies of instruments we will use are found in Appendix B, including core data elements for caregiving research suggested by the Palliative Care Research Cooperative Group.[129]

Table 1 summarizes the concepts, variables and measures, and timing of data collection. Data, including sample characteristics (age, sex, race/ethnicity, marital status, education, how long the FCG has been providing care to the care recipient, any computer/Smartphone experience and availability) and questionnaires, will be collected by a study coordinator from all enrolled participants after obtaining consent (baseline) via in-person interviews prior to the care recipients' hospital discharge.

Self-reported data will be obtained by computer-assisted interviews, telephone or mailed questionnaires, based on FCGs preferences, from all FCGs at 2 weeks, at the end of the intervention period (Aims 1 and 2) and at 6 months (Aim 2). If FCGs choose to complete questionnaires independently, they will have the choice of receiving a packet by mail or a link to complete questionnaire electronically via REDCap. If any FCG would like assistance completing the questionnaires, the study coordinator will provide assistance. Given the complexity of cost data, participants will be telephoned monthly for 6 months post-hospital discharge for cost data collection needed to address Aim 3.

If the care recipient dies, we will collect Aims 1 and 2 outcomes data from the FCG approximately 2 weeks later, given that grieving family members' distress and satisfaction with care should be more stable 2 weeks after their loved one's death.[157,158]

In order to assure the safety of participants, the intervention nurse or study social worker will follow up by phone with all participants, regardless of, who report a score of >10 on depressive symptoms on any questionnaire or if an intervention or control caregiver reports via phone, survey or email information that raises the concern for elder mistreatment or abuse about family or interpersonal conflict with potential violence or risk for self-neglect. Standard best practice protocols on assessing depression risk and self-harm will be followed. These include:

a. General and specific screening tools about neglect or mistreatment will be completed [redacted]

a) With any suspicion of risk for self-harm, violence, or safety, the person with the closest knowledge (who talked or visited with the care recipient or caregiver) immediately contacts MN, WI or IA Adult Protective Services.
b) Police will also be contacted if there is an imminent or immediate threats
c) If intervention nurse or study social worker determine no suspicion for harm, coping skills and resources are discussed and when necessary, referral to palliative care/hospice team social worker.
d) All conversations and decisions are documented into study records.

Table 1. Framework concepts, variables, timing, and estimated burden

Concepts	Variables and Measures	Timepoints	Estimated Burden
Sample Characteristics			
	Age, gender, race/ethnicity, marital status, education, relationship of FCG to care recipient, how long the FCG has been providing care to the care recipient, any computer/Smartphone experience and availability, diagnoses, medications,	Baseline	2-6 minutes
Properties of the Transition			
	Mutuality,[134] Single items for relationship of FCG/care recipient; Caregiving demand[129]	Baseline	2-6 minutes
Transition Conditions (Facilitators or Barriers)			
Characteristics	Spiritual/Religious beliefs,[128] Time available for caregiving (FCG Responsibilities & Demands),[129] Decision making preference,[130] Health literacy,[131] Income (single items), FCG Support Needs,[132] Hospital Discharge Readiness,[133] FCG Personal Health Problems[129]	Baseline	5-12 minutes
Patterns of Response (Outcomes)			
Aim 1	Preparedness for caregiving,[134] Communication skills,[135] Satisfaction with care - CG-PACIC[136,137]	Baseline, 2, & 8 weeks	6-10 minutes
Aim 2	Quality of Life (CG QOL Scale-Cancer),[9,138] Coping,[139] Depression,[140] Burden (Bakas Caregiving Outcomes Scale),[159] Patient Outcome Scale-Carer[160],	Baseline, 2, & 8 weeks	17-20 minutes
Aim 2	Depression,[140] Burden (Bakas Caregiving Outcomes Scale),[159] Positive Aspects of Care (6 months only); open-ended study satisfaction	6 months	6-10 minutes
Aim 3	Healthcare Utilization and Cost (Ambulatory and Home Care Record)	Monthly, 6 months	30 minutes

Properties of the transition. Guided by the theoretical framework for the study, measures of properties of the transition include the quality of the FCG/care recipient relationship (Assessment of Mutuality[121,134,161-163]) and caregiver demand (hours of caregiving and length of time caregiving[129]). Variables related to the properties of the transition serve as control variables or will be considered as covariates in the analysis.

Transition conditions (facilitators and barriers). Measures of facilitators/barriers also serve as control variables and include spiritual/religious beliefs,[128] time available for caregiving (due to other FCG responsibilities and demands),[129] decision making preferences,[130] health literacy,[131] income, FCG support needs,[132] readiness for hospital discharge[133] (measured at hospital discharge), and FCG personal health problems (if any).[129]

Aim 1: Evaluate the effect of a technology-enhanced TPC care model on caregiving preparedness, communication with clinicians, and satisfaction with care for FCGs.

1. Preparedness for caregiving. The Preparedness for Caregiving Scale[134,161,163] captures how well FCGs feel they are prepared for the multiple aspects of the caregiving role, using a 4-point response set ranging from 0 (“not at all”) to 4 (“very well”). A mean score is calculated; higher scores indicate greater preparation for caregiving.[163] Cronbach alphas of 0.88-0.93 are reported.[163]

2. Communication skills. The Communication with Physicians scale[164] will be used to measure the communication skills of the FCG. Originally designed for chronic disease self-management behavior, the scale has 3 questions targeting how often the FCG prepares a list of questions for the doctor, asks questions, and discusses personal problems across a 6-point response set ranging from "never" to "always." Scores range from 0-5 with higher scores indicating better communication. Internal consistency and test-retest reliability coefficients are good (0.73, 0.89, respectfully).[164]
3. Satisfaction with care. A modified version of the Patient Assessment of Chronic Illness Care (PACIC) will be used to obtain FCG perceptions of the quality of chronic illness care received by the care recipient, as used by Wolff and colleagues.[137] The PACIC was originally developed to measure patients' perspectives of the care they had received for their chronic illness, based on best practices as described in the Chronic Care Model.[165] The PACIC consists of 20 questions with 5 subscales: (1) activation, (2) delivery system design, (3) collaborative goal setting, (4) problem-solving, and (5) follow-up/coordination.[165] Scoring is a total mean score and a mean score for each subscale. Internal consistency (Cronbach alpha) for the overall score is reported as 0.96.[165-167]

<u>Aim 2: Evaluate the effect of technology-enhanced TPC on FCGs' quality of life, burden, coping, and depression</u>.

1. Quality of life. The Caregiver Quality of Life Scale – Cancer (CQOL–C) will be used to measure FCGs' quality of life. The CQOL-C is a 35-item self-report measure of the impact on the caregiver's physical, emotional and spiritual well-being and on the relationship with the care recipient.[138] Scores range from 0-140; higher scores indicate worse quality of life. Cronbach alpha of 0.91 is reported in cancer and palliative care caregivers.[9,168]
2. Burden. The Bakas Caregiving Outcomes Scale-Revised (BCOS-R) will be used to measure the burden placed on FCGs in caring for their loved ones. The BCOS-R contains 15 items that measure changes as indicators of the effect of caregiving on FCGs' lives.[169] The response set uses a 7-point Likert scale that ranges from "changed for the worst" to "changed for the best." Higher scores indicate more positive caregiver outcomes.[168] Cronbach alphas range from 0.81 to 0.90.[159]
3. Coping. The Post Discharge Coping Difficulty Scale (PDCDS) is an 11-item scale used to measure the degree of difficulty in coping with stress, recovery, self-care and management of medical needs, help and emotional support needed, confidence in self-care and medical management abilities, and adjustment after hospital discharge.[170,171] The items are measured on an 11-point rating scale with higher scores indicating greater coping difficulty. The FCGs will rate the items on a scale of 0 ("not at all") to 10 ("extremely, completely, or a great deal"). The PDCDS is reliable whether self-administered or completed by interview. The instrument measures important, yet often overlooked, factors that contribute to poor post-acute recovery experiences, which are recognized as important factors likely to impact readmission and ED visits.[172-174] Exploratory factor analysis indicates a single dominant factor accounting for 39% of scale variance.[175] Reliability in adult populations is reported from 0.81[139] to 0.87.[175]
4. Depression. Depression will be measured with the 10-item Center for Epidemiological Studies Depression Scale (CESD-10). The CESD-10 has been used as a screening tool for depression in studies with elderly patients[176] as well as patients with chronic conditions.[177,178] The correlation between this instrument and the original CESD, which had 20 items, is high.[178] The CESD-10 reliability statistics are comparable to those for the original CESD.[176] Higher scores indicate greater depressed mood. Scores of 10 or greater indicate clinically significant depression. Reliability coefficients are high (0.85-0.91).[179]
5. Positive Aspects of Care will be measured using Tarlow et al's Positive Aspects of Caregiving Measure.[166] This instrument has been used in large, diverse samples of caregivers and has shown high reliability coefficients (0.89) Examples of questions include, "Providing help to my care recipient has made me feel more useful" and "made me feel good about myself."
6. Satisfaction with study. An open-ended question that assesses participant satisfaction with participation in the study is included in the 6 month survey. Answers to these questions will provide insight into the participant experience and allow for improvements in study execution.

<u>Aim 3: Examine the effect of technology-enhanced TPC for FCGs on healthcare costs</u>. The Ambulatory and Home Care Record (AHCR) will be used as our healthcare cost measure. The AHCR is designed to capture costs from a societal perspective, implying that costs from all stakeholders (FCG, care recipients, and health systems) will be collected. Developed for the Canadian health system where healthcare is primarily publicly funded,[1] the AHCR will be modified for our study to collect expenditures paid for by any type of payer (e.g., commercial, government, or other insurance; and self-pay/no insurance) instead of simply publicly-financed expenditures as in the original AHCR. Third party insurance refers to any supplemental insurance over and above the primary insurance that the patient has (see Table 2). Thus, the proposed change to the original AHCR measure is only to increase clarity regarding funders and therefore we do not anticipate any threat to the AHCR's validity. The AHCR captures self-reported utilization and cost information for care provided by all FCGs and other unpaid caregivers, paid care received at home (e.g., home health care) and outside of the home (e.g., doctor/therapy appointments),as well as medications, supplies, and equipment. Out-of-pocket costs refer to all care-related expenses not paid for by the insurance. These data will be collected monthly for 6 months following each care recipient's discharge from the index hospitalization to minimize recall bias and to account for any time lag in billing systems. The FCGs will be prompted to have all bills received during the preceding month available during the monthly AHCR data collection. Agreement between care recipients' reports on the AHCR and administrative data range from moderate (kappa=0.41; 95 percent confidence interval, 0.16–0.61) for physician visits to perfect (kappa=1.0) for physical therapy visits.[25]

We will report these measures, per subject, every month to minimize the impact of patients dying in the earlier part of the intervention interval. The difference in costs of readmissions and ED visits between the intervention and control patients will provide an estimate of the costs avoided due to the proposed intervention. We anticipate that some care recipients will die before 6 months and therefore we will need to address right censoring of utilization and costs due to patients dying before the end of the study. Accordingly, we will adopt appropriate econometric methods as described in the **Analytical Plan section below** to account for the possible censoring of utilizations and costs.

The time costs refer to the FCGs' time and, if the FCG is employed, the employer time lost in the course of providing care to the care recipient. Time costs for the FCGs will be valued by a human capital approach.[180] The most recently available data on current earnings by age and sex from the Bureau of Labor Statistics (BLS) will be used to impute the market value of time withdrawn from leisure and household work. In order to value lost time from the labor market, age- and sex-based earnings from the BLS will be adjusted for employer-paid benefits, vacations days and holidays.

Table 2: Modified Framework for Assessment of Palliative Care Costs[1]		
Expenditure Category		
Third party-incurred Costs *(Commercial/ Medicare/ Medicaid/ Other/ No Insurance)*	***Privately-incurred Costs***	***Time Costs***
3rd Party Insurance Reimbursement (Yes/No)	*Out-of-Pocket*	*Caregiver lost time from*
• *Home-based services*	• *Home-based services*	• *Labor Market*
• *Ambulatory appointments*	• *Ambulatory appointments*	• *Household work*
• *Hospitalization*	• *Hospitalization*	• *Leisure*
• *Emergency Department Visits*	• *Emergency Department Visits*	
• *Facility care*	• *Facility care*	
• *Medications*	• *Medications*	*Employer Time Loss*
• *Supplies and Equipment*	• *Supplies and Equipment*	
	• *Paid house work*	
	• *Travel expenses*	
Total 3rd party Expenditures	***Total Out-of-Pocket Expenditures***	***Total Time Cost***

For those FCGs who are not employed outside the home, their time lost from household work will be imputed at the hourly earnings rate for the “personal care and service occupations” category in the BLS. Thus, the proposed valuation of the lost time will be a function of whether the time is diverted from the labor market, household work, or leisure. Dr. [redacted] (Co-I) will lead all aspects of this Aim.

Analytical Plan

Assessment of possible imbalances in the baseline covariates that may occur between the two groups, due to randomized intervention assignment, will be made by comparing the baseline characteristics between the two groups. Categorical variables will be compared using a Chi-square test or Fisher’s exact test; continuous variables will be compared using a two-sample t-test or the Wilcoxon rank sum test, as appropriate. All analyses will be 2-sided with an alpha level of P<.01 for significance to account for multiple comparisons and endpoints. The intent to treat analysis will serve as the principle analysis set for efficacy assessments.

Aims 1 and 2. Statistical analyses of Aims 1 and 2 will be performed in a similar manner. Every FCG will be evaluated using various scales and survey instruments at baseline, 2 weeks, and 8 weeks post patient discharge (Table 1). We will use a response-feature analysis as our primary approach in analyzing these repeated measures data.[181] For each FCG, the magnitude of the scores from the respective instruments will be plotted versus time (measured in months); least squares regression will be used to estimate a participant-specific rate of increase in points per month. This slope parameter estimate will be used as the response feature for each participant and is the primary endpoint for this study. The primary analysis of this endpoint will be analyzed using a two-sample t-test or Wilcoxon rank-sum test, as appropriate. The endpoints will also be analyzed using a fixed-effects linear regression model. This model will use the estimated regression-slope response-feature as the dependent variable and have independent variables consisting of intervention (yes, no) as well as any baseline covariates such as FCGs’ age, employment status, etc. These analyses will adjust for any possible imbalances in these baseline covariates among FCGs that occur due to the randomized assignment to the intervention. This analysis approach will hold for those endpoints collected only at two time points (i.e., baseline and 8 weeks).

Aim 3. Descriptive statistics, including mean, median, and standard deviation (minimum and maximum) for the utilization measures (i.e., hospitalizations and ED visits) will be provided. Considering the count nature of the utilizations, and to also account for any potential differences between the baseline characteristics of the care recipients in the two study arms, we will use Poisson regression to model various utilization outcomes.[182] We expect that the gains (decreased healthcare utilization and costs) will be sustained beyond the enrollment period. Therefore, both descriptive and multivariable-adjusted measures will be estimated for the intervention period and the subsequent months post-intervention. A limitation of this economic approach will be the memory recall of the FCGs. We will provide a worksheet similar to Table 2 for all participants to help them track services and costs.

For analyses of costs, standard descriptive statistics including mean, median, standard deviation, minimum and maximum will be provided for all cost outcomes measured individually and also for the overall cost measure. The difference in overall cost between the intervention and control group will provide an estimate of the cost impact of the TPC for FCG model of care. The difference in hospitalization and ED costs between the treatment and control arms will determine the cost avoidance potential of implementing the intervention. The difference in FCG cost, a component of the overall costs, between intervention and control groups will provide evidence on the impact of the intervention on this specific cost component. Both the descriptive and multivariable-adjusted measures will be estimated for 8 weeks and 6 months. Because the distribution of healthcare costs and length of stay (LOS) are generally skewed, both the LOS and costs will be log-transformed before any estimation; the estimated coefficients can then be interpreted as the approximate percentage changes. Alternatively, we will also explore modeling costs and LOS with a generalized linear model with gamma distribution and log link.[183] Furthermore, to account for the possibility that some of the study patients will die before the six-month follow-up; we will also apply econometric methods of censored regression.[184,185]

Data Management

Following the data safety monitoring plan (see Protection of Human Subjects), the PI and investigative team will review the data to ensure quality, adherence to study procedures, and safety at monthly study team meetings. All participant data will be coded and stored in a secure, locked cabinet in the study coordinator's office. All data will be entered into the web-based Research Electronic Data Capture (RED-Cap) database and maintained on secure, password-protected servers, accessible only to members of the study team. The database will be exported to the statistical analysis package, SAS, to be analyzed anonymously, and standard Mayo Clinic policies and safeguards will be used to protect the confidentiality of the subject records.

Expected Outcomes

The expected outcome of this study is an effective intervention to improve FCGs' transition experiences, maintain their health and well-being, and decrease overall costs of providing TPC. This new knowledge will provide valuable information about TPC for FCG as a sustainable foundation for TPC models, and extend transitional and palliative care science to contribute to the National Institute of Nursing's strategic plan priority of gathering evidence of effective palliative care/end of life interventions to compassionately support FCGs of patients with life-limiting illness.

Potential Problems & Alternative Strategies

The primary challenges in completing this study in a timely manner are recruitment of FCG participants during their care recipients' hospital stay and completion of data collection after hospital discharge. We have identified the following strategies to overcome these potential problems.

Recruitment. Drs.Griffin has more than 15 years of experience achieving enrollment goals utilizing recruitment methods similar to those we will employ for this proposed study.[186-189] One specific strategy is targeting recruitment during mid-day and early evening, facilitating patient and FCG availability. We have developed strong, ongoing relationships with the Palliative Care consulting teams, who have ongoing relationships with the patients and their FCGs on their caseload. These clinically based partners will also encourage study participation.

Data collection after hospital discharge. Data collection will be completed based on FCGs' preferences using computer-assisted face-to-face interviewing, telephone interviewing, or mailed questionnaires with a stamped pre-addressed return envelope. A cover letter will accompany the questionnaires sent by mail or administered via REDCap, requesting that the FCGs complete the questionnaires on the same day they receive them, if possible. The study coordinator's phone number will be included, along with the offer to administer the questionnaires over the phone or via computer, if preferred. To minimize missing data, the study coordinator will make repeated attempts to collect the data at the respective time points.

To assure maximal completeness of post-discharge data, the study coordinator will request at least 2 phone numbers (typically home and cellphone number) for all FCGs, as well as the name and phone number of another person who may know their whereabouts. Follow-up calls to schedule data collection will be made approximately 2 weeks and then monthly after hospital discharge at the number and time of day the FCGs suggest. Depending on the participant’s preference, they may choose to be contacted by text message or email instead of receiving a phone call. The study coordinator will use a cell phone with caller identification recognizable to the participants to assure completeness of follow-up data. If at first we are unable to connect, phone calls will be made at varying times during the day. Our prior experience related to completion of data collection after hospital discharge indicated that the majority of patients and FCGs do not venture far from home soon after discharge. We will provide remuneration to all FCG participants commensurate with the time spent in the study (intervention activities for intervention group, data collection for both groups) to encourage continued engagement. If a care recipient dies during the data collection period, it may be difficult to collect subsequent data from the FCG. Providing reminder phone calls as an attention control device will augment the continued engagement of control FCGs in the study. Recall of cost components will be enhanced by monthly data collection up to six months after the care recipient’s index hospitalization to account for any time lag in billing systems. The FCGs will be provided a checklist and prompted to have all bills received during the preceding month available during the monthly AHCR data collection.

Resource Sharing Plan/Data Sharing Plan

The research will be disseminated at national scientific meetings, and manuscripts will be generated from the Specific Aims. A clean de-identified dataset will be available to qualified investigators through communication with the PI after primary results manuscripts are accepted.

C. Timetable

STUDY TIME LINE	**Year 1**				**Year 2**				**Year 3**				**Year 4**				**Year 5**			
Tasks	**Q1**	**Q2**	**Q3**	**Q4**	**Q1**	**Q2**	**Q3**	**Q4**	**Q1**	**Q2**	**Q3**	**Q4**	**Q1**	**Q2**	**Q3**	**Q4**	**Q1**	**Q2**	**Q3**	**Q4**
Study start-up: regulatory & training	▨	▨																		
Subject accrual & data collection			▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨				
Data Analysis													▨	▨	▨	▨				
Cost Analysis															▨	▨	▨			
Dissemination & final report												▨				▨		▨	▨	▨

D. Future Directions

Caregiving today is “more complex, costly, stressful, and demanding than at any time in human history.”[4] The findings from this study will be foundational to creating effective linkages across healthcare settings and among providers by addressing FCGs’ needs as they transition from the hospital to providing care to their loved ones at home. Our findings will advance the development of TPC models of care to optimize outcomes for palliative care patients and their families who live in underserved areas. Future efforts will focus on dissemination and implementation of our technology-enhanced TPC model to benefit the greatest number of FCGs to meet their needs and improve their health and well-being.

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APPENDIX A: Intervention

Technology-Enhanced Transitional Palliative Care for Family Caregivers in Rural Settings Detailed Intervention Protocol

Part 1. Pre-discharge

- Hospital visit within 24 hours of study enrollment
  - Establish relationship with family caregiver (FCG) and care recipient (if able)
  - Assess FCG needs including: knowledge and skills needed for skillful caregiving, FCG physical and emotional self-care needs, involvement of secondary caregivers and/or formal service providers to support the FCG
  - Begin transitional care planning with acute care staff, FCG and local community service providers
- Daily hospital visits to patient
  - Work with FCG, multidisciplinary palliative care team, and community providers to complete Transitional Care Plan identifying local community resources to support caregiving including:
    - Caregiver/respite availability
    - Medication availability and plans for refills
    - Transportation home and to medical appointments
    - ADL support (as needed) including, personal care assistance, food availability/meal preparation, housekeeping
    - Equipment needs/delivery
    - Crisis prevention plan consistent with caregiver/care recipient goals
- FCG Readiness Plans
  - Develop individual-specific Readiness Plans to support FCG to effectively manage care-recipient's symptoms
    - FCG Readiness Plans available for dealing with: anxiety, breathlessness, constipation, hypoglycemia, restlessness, shortness of breath.
  - Develop individual-specific Readiness Plans to support self-care of FCG
    - Examples of self-care plans include Caregiving Care for Yourself, Lack of Sleep, Mindful Breathing, Managing Anxiety/Uneasy Feelings
- Day of discharge
  - Confirm FCG and patient readiness for discharge – understanding of patient care needs, physical and emotional readiness for caregiving, plans for FCG self-care and respite are in place
  - Assure Palliative Care Team consensus on post discharge FCG Readiness Plans to support caregiver activities on behalf of the patient
  - Implement and coordinate Transitional Care Plan
  - Schedule first virtual visit
- Document all problem-related assessments/interventions for each FCG encounter on study documentation forms

Part 2. In-Home

- Provide ongoing education, guidance and support to FCG for Transitional Care Plan to develop caregiving skills described above
- Coordinate the implementation of transitional care plan
  - Communicate with local community resources to assure support services are in place and effective
  - Reassess continued appropriateness/outcomes of FCG Readiness Plans
  - Identify and address any new problems that develop
- Reaffirm and provide education and anticipatory guidance for use of appropriate FCG Readiness Plans
- Collaborate with primary care provider/specialty provider who will provide primary care related to goals of care
- Coach FCG in preparation for care-recipient physician office visits
- Provide additional virtual visits/phone calls to support FCG as needed during:
  - Transfer to hospice
  - Permanent nursing home placement
  - Death of care-recipient
- Document all assessments/interventions for each FCG encounter on study documentation forms
  - The pre-discharge protocol will be reinstituted for the duration of the hospital stay. Virtual visits will begin again after hospital discharge.

Review case weekly with palliative care study team members (MD, SW, Pharm)
Final virtual visit - complete FCG transition to ongoing family, community and health care support
If patient is rehospitalized during the 8-week study period

Conducting TPC for FCG Intervention
Initial and Ongoing during Part 1 and Part 2

Assessments and Monitoring – Assess FCG's priority emotional, self-care needs and caregiving support needs

- Psychosocial
  - Mental health – anxiety or depression
  - Grief/anticipatory grief
  - Spirituality
  - Communicating with Healthcare & Community Resources
  - Social Contact
  - Role Change
  - Interpersonal Relationship
  - Other
- Self-Care Needs
  - Nutrition
  - Physical activity
  - Sleep and Rest
  - Personal care
  - Condition specific needs (cardiac, respiratory, pain etc.)
  - Medication regimen
  - Residence (fall risk/ safety risks)
- Caregiving Support
  - Caregiving skills
  - Continuity of care
  - Coping skills
  - Support system

Care Coordination/Transition

- Provide coordination, advocacy and referral for FCG during transition in collaboration with the palliative care team, other specialists, community services providers and other staff:
  - Facilitate community services for symptom management - medication availability, plan for refills, correct use
  - Communicate with health care and community service providers across care settings
  - Develop connections between family, primary care physician, specialists
  - Guide the FCG in the use of appropriate community resources
  - Promote FCG/provider/community communication
  - Coordinate care needs and community resources
  - Ensure food availability – services in place to obtain food and prepare meals
  - Facilitate decision to access hospice services as needed
  - Arrange for emergency services consistent with patient goals
  - Arrange for respite care as needed
- Transition to usual care
  - Create a transition plan to usual care (local primary care or other health provider)
  - Create a post-transition care management plan
  - Provide a written summary of care to transition team (palliative care, primary care, oncologist, social worker, minister etc.)

Teaching, Counseling and Guidance

- Provide teaching, counseling, guidance regarding FCG educational needs and support that impact effective caregiving and a safe transition home
- Determine family priorities and learning needs. Provide ongoing education to support development of caregiving skills:
  - Monitoring patient, subtle changes, written record
  - Interpreting changes, understand the meaning of symptom changes
  - Decision making considering multiple illness demands, self-care needs
  - Taking action - timing, routines, reminders

  - Making adjustments – food, environment, creative problem-solving
  - Accessing resources – takes initiative, makes needs known
  - Providing hands-on care
  - Working together with the care recipient
  - Negotiating the health care system
- Provide ongoing education and support for use of Readiness Plans to: LIST ALL PLANS HERE
  - effectively manage care-recipient's symptoms (anxiety, breathlessness, constipation, hypoglycemia, restlessness, seizures, shortness of breath and urinary tract infection)
  - Promote FCG self-care
- Educate FCG about disease process, trajectory and care and safety needs
- Set realistic interim goals for achieving preferences
- Assure FCG understanding of prescribed instructions/therapies
- Promote FCG adaptation by focusing on coaching, education, problem solving, and enlisting support of family/friends in Education
  - maintenance of health and well-being and safety measures
  - teach strategies to maximize self-care
  - enlist support of family/friends/agencies to compensate for FCG time or functional deficiencies to provide care
  - counsel on need for consistent self-care activities to maintain health, well-being
- Teach and build caregiver skills in navigating health system to meet needs
  - understand meaning of symptoms
  - understand roles and responsibilities of various formal providers of care
- Teach communication skills
  - strategies to communicate effectively with healthcare providers and gain access to care when needed
  - clarification of goals/preferences of care and consequences of decisions
- Assist with resources for ethical and legal aspects of care
  - discuss advance care planning
  - assure patient treatment goals are transferable and applicable across care settings
- Psychosocial Guidance and Support for FCG
  - Promote mental health:
    - establish strategies to manage anxiety, depression
    - establish strategies to address psychological reactions of patient/FCG/family (stress and coping)
    - provide education and guidance to enhance FCG coping skills for responding to patient problems such as problem behaviors, anger, depression
  - Provide support for anticipatory grief
    - Grief plan
  - Foster quality of relationships and support systems
    - support spirituality
    - patient story – sense making
  - Promote use of Readiness Plans related to FCG self-care
  - Help caregiver connect with a community resources, support group as appropriate – face to face or on-line
  - Reduce amount of caregiving: encourage/arrange respite – in home, day care, institutional for holidays, temporary illness of caregiver, other demands
  - Advance care planning – goals of care

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Basic Tips in Caring for a Loved One at Home

Develop a plan

It’s important to always think both short term (prescriptions are due for refill) and long term (the “what ifs”). You can’t anticipate every scenario, but being forward-thinking now will help you respond more quickly and effectively in an emergency. And don’t go it alone. Reach out to form a larger team of family, friends and others who can help you.

Quick Tips:

- Determine tasks and find consensus. Ask team members what they’re willing to do to contribute to your loved one’s care. Even if they live far away, they can handle jobs like paying bills, ordering prescriptions and scheduling medical appointments. Work with the team on a plan.
- Be honest with yourself. What are you prepared to do? If you are uncomfortable with hands-on caregiving tasks, such as helping a loved one bathe, ask if another team member can step in. Or discuss whether there is money available to hire assistance.
- Summarize the plan in writing. A written record will ensure that everyone on your team, including your loved one, is on the same page and avoids misunderstandings (while remembering, of course, that the plan will likely evolve as time passes).

Manage health care needs

Because hospitals have been discharging patients more abruptly to cut costs, tasks once reserved for nurses are now often handed off to caregivers, who sometimes get little or no training or instruction. Meanwhile the caregiver may be trying to keep track of a confusing mix of medications for a range of different ailments. The key is to stay organized and know how to get the help you need.

Quick Tips:

- Stay on top of meds. Create and maintain an updated medication list, with the name, dosage, prescribing doctor and other relevant information — a handy document to bring to medical appointments. AARP’s Rx app is one easy way to manage both your and your loved one’s prescriptions.
- Be ready to handle medical tasks. Many family caregivers are required to handle challenging tasks at home, such as injecting medicines and inserting catheters. It’s important to get detailed instructions and even a demonstration of how to perform the procedure before you leave the hospital.
- Set up home health services. Medicare and some other insurance plans will cover certain in-home services deemed medically necessary — such as doctor/nurse visits, X-rays, lab tests or therapies. A patient who is considered homebound, or unable to make an office visit, qualifies for these services on an ongoing basis.

A healthy lifestyle

Especially if you are sharing a home with the person you’re caring for — most likely a parent or spouse — caregiving can become all-consuming. You may find yourself playing nurse, coach, nutritionist and social director. All of these roles are important for maintaining your loved one’s mental and physical health. Just don’t neglect your own.

Quick Tips:

- Address social needs. Isolation and loneliness are associated with poorer health — so helping your loved one (and yourself!) avoid them is a key part of caregiving. You might find a community arts program for seniors, invite friends and family members to visit, or go out to eat together.
- Manage nutrition. Be conscious of any dietary restrictions, and encourage your loved one to maintain a balanced diet, avoiding processed foods. Look into home-delivered meal programs and be sure your loved one drinks plenty of fluids; dehydration can cause fainting, headaches and more.

- Encourage exercise. Staying mobile is crucial for maintaining — among other things — strength, balance, energy and brain health. Your loved one's abilities will vary, and you should check with a doctor, but the routine may include activities such as walks, seated yoga, swimming or lifting small weights.
- Establish boundaries. Especially if you and your spouse/partner are living with the person you're caring for, it's important that everyone has a level of privacy. Ideally, there is some separation between living areas and you can manage some time together as a couple.

Get help

Depending on the severity of your loved one's problems, if you're the primary caregiver you're going to need either a bit of assistance or a whole lot of it. Rely on your team for help with some caregiving tasks and to fill in so you can take breaks. Don't feel guilty: Your own health — and the quality of your caregiving — will suffer if you try to do everything and don't take time to care for yourself.

Quick Tips:

- Understand caregiving's costs: Your personal finances can take a hit from family caregiving—which might require time off of work, cutting back on hours, or passing up promotions, as well as paying for things like groceries and prescriptions for your loved one from your own pocket. Try to calculate these costs when budgeting.
- Find out if your workplace is accommodating: Your employer may be fine with your working from home part- time or making certain adjustments to your schedule. If you need more time off, consider asking whether you are covered by the Family and Medical Leave Act. (Many are, but if you work for a small company or haven't worked for your employer long, you may not be eligible.)
- Give yourself a break: Sometimes caregivers feel guilty about taking time to have fun. Find ways to reduce your stress and enjoy yourself. Many turn to yoga or meditation, or arrange a weekly movie outing with friends. Think about what activities you find relaxing and/or energizing and put them on your to-do list.
- Ask friends and family members for help. There are plenty of people in your life who may be happy, or at least willing, to lend a hand if you simply ask. Maybe someone can pick up a prescription for you on the next trip to the store, or a neighbor might stop by with dinner once a week.
- Farm out some household jobs. Consider paying for relatively small services that will take a big load off, such as a weekly housecleaner, yard care or grocery delivery. If you live apart from your loved one, you might do the same for your own home.
- Hire in-home care. You can go through an agency or hire a caregiver directly, but either way, be sure to check references and background, then monitor performance carefully (cautionary tales abound). It's smart to rely on word of mouth; ask fellow caregivers for recommendations.
- Watch your mental health. As a caregiver, you are at a higher risk for stress and depression. If either grows serious, seek help from a mental health professional. And consider reaching out to other caregivers for support and advice.

Adapted from AARP Caregiving Guides (http://www.aarp.org/home-family/caregiving/care-guides/caregiving-at-home.html#step1) and AARP Care-giving guides for first-time caregivers (http://www.aarp.org/home-family/caregiving/care-guides/first-time-caregiving-guide.html#step5)

Lack of Sleep: Energy Boosters for Sleepy Caregivers

Avoid quick-fix snacks

When your body is sleep-deprived, it craves carbohydrates and foods high in glucose or sodium. Snack foods like cookies, doughnuts, candies, crackers and chips taste good, but are just a quick, short-term energy fix. Ultimately, your body experiences a letdown. Likewise, eating too much of these foods is simply not healthy and can lead to an unwanted weight gain — so steer clear of these tasty snacks. Instead, eat an apple, orange, banana or a handful of nuts to satisfy your hunger and provide energy in a healthy way.

Eat small, healthy meals

A large, calorie-rich meal can make you feel sleepy and sluggish. Try eating several smaller meals throughout the day, and be sure to include high-protein foods. Protein provides and sustains energy for a longer time than simple carbohydrates.

Consider enjoying one of these smaller, lighter meals:

- Low-fat peanut butter spread on celery and apples
- Scrambled egg whites served with a side dish of fresh fruit and whole-wheat toast
- Tuna salad topped with lettuce and tomato on whole-wheat bread or pita
- A cup or smoothie of low-fat yogurt mixed with blueberries or strawberries

Don't overdo caffeine

When you're tired and know you have many daily chores to do for your loved one, it may be tempting to double or triple your daily amount of caffeine. Unfortunately, it's likely this increase will keep you awake when it's time to go to sleep. Instead of upping your caffeine quotient, stick with the amount of caffeine you normally drink during the day, followed by a good night's rest.

Grab a nap

Napping is healthy. Studies show that an occasional short snooze may decrease a person's risk of coronary heart disease. If you can, make time for a nap. But be sure another person is present in your home to care for your loved one, particularly if he or she has special needs that require constant attention.

Refresh with a cold shower

While a soothing, hot shower may sound good, it can leave you sleepy. Instead, take a quick, cold shower or wash your face with cool water. This refreshing and revitalizing break can make you feel better all over and ready to take on your next caregiving task.

Walk for 30 minutes

A brisk walk can physically and mentally recharge you. It brings fresh, oxygenated blood to your muscles and organs, boosts your metabolism and lifts your spirits. This added energy can help sustain you throughout the day.

Drink water

Water is essential to your body's good health. Fifty-five to 60 percent of the average body is made up of water. Drinking water throughout the day protects you from dehydration. Mild dehydration (as little as a 1 to 2 percent loss of body water) can reduce your energy and cause weariness, making caregiving responsibilities even more challenging.

Stay safe

After a sleepless night, you should also recognize that you may have some limitations. Avoid activities that could compromise your safety and that of your loved one, such as:

- Driving — especially for long distances. Driving is dangerous when you're tired. So if you need to take your loved one to a doctor's appointment or pick up a prescription at the pharmacy, you may want to reschedule or ask a friend for a ride.
- Drinking alcohol — don't! It can make you even sleepier and compromise your caregiving duties.
- Smoking — once again, don't! Many household fires are caused when someone falls asleep while smoking.

Plan ahead

Keep these survival tips in mind when you know you'll have to pull an all-nighter.

- If you work outside the home, ask your boss if you can come in late the next day.
- If you have children, ask if a neighbor can watch them. This can give you a few hours of relief before you have to stay up all night.
- Arrange for another person to provide caregiving services to your loved one the next morning.
- Try to get a good night's rest the night before.

Adapted from AARP caregiver guides (http://www.aarp.org/home-family/caregiving/info-2014/energy-boosters-sleepy-caregivers.html)

Mindful Breathing Stress Reduction

Mindfulness is paying attention in a particular way: on purpose, in the present moment and nonjudgmentally. The practice of mindfulness leads to stress reduction through several mechanisms: (1) paying attention on purpose interrupts automatic negative thoughts; (2) paying attention in the present moment reduces rumination and worries; and (3) paying attention nonjudgmentally minimizes negative evaluations of the situation.

Instructions:

Make yourself comfortable. Relax your body.

Close your eyes gently.

Take two deep breaths slowly. Then breathe naturally.

Notice the flow of air through your nose. Rest your attention gently on the breath.

If you are distracted by any sounds, body sensations, thoughts or feelings, gently come back to your breath.

Be aware of the breath for the next five minutes.

Beng TS, Ahmad F, Loong LC, Chin LE, Zainal NZ, Guan NC, Ann YH, Li LM, Meng CB. Distress Reduction for Palliative Care Patients and Families With 5-Minute Mindful Breathing: A Pilot Study. The American Journal of Hospice & Palliative Care. 2016;33(6):555-60. doi: 10.1177/1049909115569048. PubMed PMID: 25632044.

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PATIENT / FAMILY TEACHING SHEET

Managing Fatigue

What is Fatigue?

Fatigue is a feeling of being tired or exhausted. Even after getting plenty of sleep or rest, people with fatigue feel like they have no energy. They are so tired that they cannot do the activities they normally enjoy. Fatigue is common among hospice and palliative care patients. Diagnosing reasons for fatigue may take time because fatigue can have many causes, including illness, emotions and treatments. Sometimes, fatigue can also come with feelings of depression or sadness.

What are the Signs of Fatigue?

- “Just too tired” to care about or do normal activities or routines
- Lack of appetite or not having energy to eat
- Sleepiness
- Not talking
- Depression

What to Report to the Hospice/Palliative Care Team?

- Any signs listed above.
- Describe how bad the fatigue is by using a number scale from 0 to 10: 0 = no fatigue to 10 = in bed all day
- What makes the fatigue better or worse?
- Spiritual, social or emotional concerns and worries.
- Changes in appetite.
- Any troubling symptoms that are not controlled, such as nausea, pain or bowel problems.
- If you have experienced fatigue before, and what made it better.

What Can be Done to Help Fatigue?

Because fatigue can have many causes, it may take a number of actions to improve your symptoms. Talk to your healthcare team about your fatigue. The team will work with you and your family to find the causes for the fatigue. They will discuss treatments that may work best for you.

Things you may do to help your fatigue:

- Slowly increase your activity. Do so a little at a time to save energy.
  - Keep a log of which time of day seems to be your best time.
  - Plan and do activities during your best times of the day.
  - Avoid or delay activities that are not your priority.
  - Change your position. Do not just stay in bed.
  - Use sunlight or a light source to help your body feel more energized.
  - Try activities that restore your energy, such as music, meditation or spending time outdoors.
  - Allow caregivers to assist you with daily activities such as eating, moving or bathing, if necessary.
  - Talk with your family about your energy level and how they can help.
- Rest and sleep better.
  - Listen to your body – rest as needed.
  - Try to keep a regular time to go to bed and to wake up.
  - Stay away from things that may keep you from sound sleep, such as lighting, or certain food, drinks and medicine taken too late in the day.
  - Avoid interrupted sleep time, and try to get continuous hours of sleep.
  - Plan rest times or naps during the late morning or mid-afternoon.
  - Avoid sleeping later in the afternoon, which could affect your nighttime sleep.
  - Ask if using oxygen when you sleep will help you to sleep better.
- Increase food intake.
  - Try nutritious, high protein food.
  - Eat small, frequent meals.
  - Add protein supplements to foods or drinks.
  - Frequent mouth care (before and after meals).
  - Ask about the possible use of medications to stimulate your appetite or relieve fatigue.

Other HPNA Teaching Sheets are available at www.goHPNA.org.

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Hospice & Palliative Nurses Association
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PATIENT / FAMILY TEACHING SHEET

Food and Fluid Issues at the End of Life

What are nutrition(food) and hydration(fluids)?

- Nutrition is the intake of calories to support the body
- Hydration is the intake of fluids to support the body

The desire to eat or drink at the end of life usually decreases. This is a natural response of the body as the organs are slowing down and it becomes difficult to manage the intake of food and/or fluids.

What to report to the hospice/palliative care team?

Tell them if the person:

- Is unable to eat or drink
- Has trouble swallowing
- Has a dry mouth, tongue, or skin
- Loses more than five pounds in a week. You may notice the weight loss by loose fitting clothes or dentures
- Makes less urine
- Becomes confused or drowsy

What can be done?

If there is a problem that can be managed, your health care team will discuss possible treatment options. It is normal for the person to lose interest in food and drink as the illness progresses. Treatment choices will depend on the person’s wishes and illness.

Things you can do:

- Encourage favorite foods and drinks, never force a person to eat or drink
- Help family members and friends understand why eating and drinking may make the person uncomfortable as the body loses the ability to use nutrition and hydration
- Offer drinks or sips often – at least every two hours
- Clean the mouth often – a pleasant tasting mouth may make food taste better
- Support the person’s decision if he/she refuses food and/or fluids

- Encourage the person to rest before and after a meal
- If dentures do not fit well, consult a dentist
- Make mealtime a quiet and pleasant time
- Offer small meals and use smaller dishes
- If nausea is a problem, serve small portions of salty (not sweet), dry foods and clear liquids
- Find other ways besides food and drink to show care and support. For example, offer the person a massage, apply lotion to his or her hands or feet, look through a picture album together

Other HPNA Teaching Sheets on are available at www.HPNA.org.

Reference

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Approved by the HPNA Education Committee August 2008
Reviewed by the Education Services Committee September 2012

**PATIENT / FAMILY
TEACHING SHEET**

Grief and Mourning

What is grief?

Grief is the normal, emotional response to a loss. Each person grieves in his or her own way. There is no right way to grieve. There is no specific timetable for completing the grief process. While grief is often associated with the death of a loved one, it may also be experienced at the time of other losses such as the loss of function due to illness, loss of a pet, loss through divorce, loss of future dreams or role changes, and many other changes in life or health.

What is mourning?

Mourning is the outward expression of grief and includes rituals and customs such as funerals, viewing of the body, cremation and other customs. Each religion, culture, ethnicity and even different parts of the same country may have different expressions of mourning.

What reactions may be expected during the grief process?

Grief affects a person's behavior, emotions, mental and physical well being. Among the physical experiences are such things as:

- Tightness in the chest and throat, breathlessness
- Headaches and dizziness
- Exhaustion or weakness
- Dry mouth
- Muscle aches

Among the thoughts are:

- Disbelief and shock
- Confusion and difficulty concentrating
- Hallucinations
- Preoccupation with the deceased

Some of the emotions that are most often felt include:

- Sadness or helplessness
- Anger, which may be directed at God, family, health care providers, or the person who died
- Shock, guilt, or anxiety

- Numbness or ambivalence
- Yearning
- Shame
- Fear

Changes in behavior may include:
- Sleeping more or less
- Eating more or less
- Withdrawal from usual activities
- Crying
- Over activity or keeping busy
- Dreaming of the deceased

What can be done to help the healing process?
- Give yourself permission to grieve
- Get plenty of rest, exercise and eat a healthy diet
- Try to have at least one close person with whom you share your feelings and receive support
- Consider keeping a journal to write down your feelings
- Don't push yourself to make changes in your life too quickly
- Reminiscing and putting together a memory book provide an active way to heal
- Get information about the normal grief process
- Attend a community grief support group

What should be reported?
- Persistent intense grief reactions months after the loss (not just occasional intense grief reactions)
- Thoughts of suicide or self-harm
- Social isolation
- Unplanned changes in weight
- Increase in use of alcohol or drugs

Your team cares about your well-being long after your loss. Take care to ensure you recover from your loss by creating a "new normal" way of life.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

Reference

Hospice and Palliative Nursing Assistant Core Curriculum. Pittsburgh, PA: Hospice and Palliative Nurses Association;2009.

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PATIENT / FAMILY
TEACHING SHEET

How to Prepare for Potential Bleeding

Why Bleeding Happens, and What to Do if It Occurs

Bleeding at the end of life can be distressing for the patient and family. Bleeding occurs for many different reasons, such as clotting disorders, tumors that erode (wear away) blood vessels, ulcers, and some lung or breathing conditions. Patients who have had previous bleeding are at increased risk for additional bleeds. It is important to have a plan in place to respond if bleeding occurs. Ask for education and support from the hospice staff. The primary goals are patient comfort, and reducing patient and family anxiety and fear.

What are the Signs of Bleeding?

- Previous bleeding from any part of the body, including the gums
- Blood-tinged coughing or vomiting
- Blood in the urine or stool
- Nose bleeds
- Skin with excessive bruising/many red dots on the skin

What to Report to the Hospice/Palliative Care Team?

Any change in frequency or quantity of bleeding symptoms should be reported to the hospice/palliative care team.

What Can be Done for Bleeding?

The hospice/palliative care team will talk to the patient and family about the chance for any bleeding and will provide help if bleeding occurs.

Tips for patients who experience bleeding are:

- Keep air humidified.
- Have bandages/dressings to apply as directed by the care team.
- Keep dark-colored towels or blankets and waterproof underpads ready for use if bleeding occurs.
- Use non-sterile gloves to clean up after any bleeding episodes.

Discuss with the hospice/palliative care team:

- Stopping any medications or treatments that can cause bleeding (aspirin, Ibuprofen/Motrin, Vitamin E).
- The use of cough medicine for patients with a cough.
- Medications that can be prescribed to lessen the problem.
- Medications already in the home that may provide sedation, anxiety relief and/or pain relief.

Your hospice/palliative care team is available to make sure you have all the education and support you need if bleeding occurs.

Other HPNA Teaching Sheets are available at www.gohpna.org.

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Approved by the HPNA Education Committee October 2008.
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Reviewed by the HPNA Professional Development Advisory Council October 2015.

Managing Anxiety/Uneasy Feelings

What is Anxiety?

Anxiety is a feeling or deep sense that things are not right. It is OK to experience anxiety sometimes. Anxiety can help people to focus on completing a task or to deal with a stressful situation. But it is not alright for people to have strong, extreme and lasting worry and fear about everyday life. People who have trouble with activities of daily living because of these feelings should ask for help to manage their anxiety.

What are the Symptoms of Anxiety?

- Fear
- Worry
- Sleeplessness, disturbing dreams or nightmares
- Confusion
- Rapid breathing
- Racing heartbeat
- Tension
- Shaking
- Inability to relax or get comfortable
- Sweating
- Problems paying attention or concentrating

What to Report to the Hospice/Palliative Care Team?

- Feelings that may be causing anxiety (like a fear of dying or worrying about money)
- Concerns about illness
- Relationship problems with family or friends
- Spiritual concerns
- Signs and symptoms that anxiety is changing or getting worse

What Can be Done to Help Relieve Anxiety?

The hospice/palliative care team will try to find the cause for your anxiety. They will talk with you and your primary care provider about treatment options.

Things you can do:

- Activities that have helped your anxiety in the past.
- Write down your thoughts and feelings.
- Treat physical problems, such as pain, that can cause anxiety.
- Try relaxing activities like deep breathing or yoga.
- Play soothing music.
- Keep your surroundings calm.
- Limit visitors.
- Massage your arms, back, hands or feet.
- Count backward slowly from 100 to 0.
- Avoid caffeine and alcoholic beverages.
- Exercise.
- Provide reassurance and support.
- Ask for help from family, friends and other members of your care team.
- Live life one minute at a time.
- Use ordered medications as prescribed.

Other HPNA Teaching Sheets are available at www.goHPNA.org.

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Reviewed by the HPNA Education Services Committee June 2011.
Reviewed by the HPNA Professional Development Advisory Council October 2015.

Managing Bladder Incontinence

What is bladder incontinence?

- Loss of bladder control causing loss of urine
- The problem has varying degrees of severity. Some people have only small leaks or dribbles of urine, while others lose large amounts of urine at a time.
- Bladder muscles and nerves as well as the brain all work together to control bladder function
  - A problem in any of these areas can result in incontinence
  - Infection, constipation and mobility problems can also cause incontinence
- Urine left on the skin can lead to irritation and odors

What can I do to control urinary leakage?

- Establish a regular pattern of urinating
  - Plan to go to the toilet every two hours while awake and before bedtime
- Make it easier to get to the bathroom
  - Use a bedside commode, urinal or bedpan
- Protect your privacy and dignity
- Avoid fluids or foods that contain caffeine (soft drinks, coffee, tea or chocolate)
- Avoid alcohol as it can over stimulate the bladder
- Ask your nurse about
  - Exercises that can help develop more control
  - Medications that may help improve bladder function

What can be done to prevent odor or skin irritation?

- Keep skin clean and dry
  - Take extra care to wash and dry the area
  - Products are available that can help you feel clean and eliminate odor
  - Use barrier creams to protect skin from urine
- Use protective products to try to keep clothing dry
  - Your nurse can help you select which type of garment and products would be most helpful for you
  - Change the garment frequently
- Wash your hands before and after care to prevent infection
- Ask your nurse for things that can further control any odors

What to discuss with the hospice and palliative nurse?

- Changes in your bladder function
  - Burning, pain or discomfort with urination
  - Changes in the amount, frequency, color or odor of urine
- Medications
  - Many medications can cause incontinence
- Skin irritation

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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orig. 09 07, rev. 05 11, rev. 09 15

Hospice & Palliative Nurses Association
Advancing Expert Care in Serious Illness

PATIENT / FAMILY TEACHING SHEET

Managing Bowel Incontinence

What is Bowel Incontinence?

Not being able to control a bowel movement from the rectum - has many causes. Some of these include:

- Weakness of the anal muscle
- Dementia
- Mobility problems
- Nervous system disorders
- Mental confusion

Other factors include:

- Long-term use of laxatives
- Not enough fluid or fiber intake
- Lack of exercise
- Hemorrhoids
- Sedation
- Very hard stool/severe constipation (may cause leakage)

What are the Signs and Symptoms?

- Losing control of a bowel movement or blockage of bowel contents.
- Symptoms may include:
  - Nonstop oozing of loose stools
  - Loss of appetite
  - Cramping

What to Report to the Hospice/Palliative Care Team?

- Color, looseness and odor of the stool
- Abdominal discomfort, cramping or bloating
- Medications and diet history
- Changes in activity level
- Skin problems of the affected area
- Concerns and thoughts from either the patient or caregiver

orig. 09 07, rev. 05 11, rev. 09 15

What Can Be Done for Bowel Incontinence?

- Know the person's bowel history which includes usual routine, time of day, following a meal, etc.
- Ask your health care team about strategies to reestablish a routine and predictable schedule for elimination.
- Plan a bowel retraining program that is easy and fits into the person's lifestyle. Your nurse can help with this.
- Take in enough fluids and fiber, if possible.
- Determining types of fluids and fiber sources pleasing to the patient.
- Provide ample time and privacy during toileting.
- Keep skin clean and dry to prevent breakdown and odors.
- Avoid baby powder and cornstarch – use protective barrier creams.
- Wear loose fitting clothing to allow for air flow.
- Control odors with fresh air and room deodorizers.
- Wear protective garments.
- Avoid foods that act as laxatives; these include caffeine, alcohol, diet soda and artificial sweeteners.
- Talk to your nurse for additional information.

Other HPNA Teaching Sheets are available at www.goHPNA.org.

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Approved by the HPNA Education Committee September 2007. Reviewed by the
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orig. 01 07, rev. 05 11, rev. 09 15

Managing Constipation

What is Constipation?

- Bowel movements occurring less often than your usual established bowel pattern
- Hard stool that may be difficult to pass
- Increased difficulty moving bowels

What to Report to the Hospice/Palliative Care Team?

- No bowel movement in two (2) days
- Any change in the frequency or consistency (e.g., liquid, pebbles) of bowel movements
- Pain, cramping, tenderness
- A feeling of fullness or bloating
- Blood in stools
- Diarrhea or oozing stools

What Can be Done?

The good news is that there are things you, your caregiver and the hospice/palliative care team can do for constipation.

The health care team will determine the underlying cause and discuss the best treatments for your constipation.

- Record when bowel movements occur. A sample Bowel Movement Record is attached to this teaching sheet.
- Follow a regular bowel regimen, even if you are not constipated. Many medications can cause constipation.
  - Drink as much fluid (liquids) as is comfortable; drinking warm liquids may promote bowel movement. Fluids are found in liquids, juices, soups, fruits and vegetables, and frozen treats.
  - Try to drink 6-8 cups daily.
  - Eat more fruits and fruit juices, including dried fruits.
  - Try to sit upright and avoid lying too much in bed.
  - Increase physical activity if possible; walking can be beneficial.
  - Take laxatives/stool softeners as ordered by your healthcare provider.

orig. 01 07, rev. 05 11, rev. 09 15

  - Sit upright on the toilet, commode or bedpan.
  - Establish routine times for toileting.
  - Avoid bulk laxatives as determined by your health team if not drinking enough fluids.
- Notify the hospice/palliative care team if constipation continues.

Other HPNA Teaching Sheets are available at www.goHPNA.org.

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Approved by the HPNA Education Committee January 2007.
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Bowel Movement Record

Date and Time of BM	Consistency Of Stool Examples include: hard, soft, liquid	Abdominal Symptoms Examples include: bloating, distention, gas, cramping, nausea, vomiting, reflux, heartburn	Problems With Passing Stool Examples include: straining, incomplete passage of stool, leakage of stool, diarrhea, hemorrhoidal pain or bleeding

Questions Or Comments For The Hospice/Palliative Care Team

orig. 07 05, rev. 01 09, 07 13

Managing Delirium

What is delirium?

- A sudden change in a person’s mental status over a period of hours to days
- Mental clouding with less awareness of one’s environment
- Confusion about time, place and person

What are the signs and symptoms of delirium?

- Reversal of sleep and awake cycles
- “Sundowning” or confusion that is worse at night
- Mood swings that may change over the course of a day
- Difficulty focusing attention or shifting attention
- Hallucinations or seeing, hearing or feeling things which are not there
- Agitation and irritability
- Drowsiness and sluggishness
- May be restless and anxious

What to report to the hospice/palliative care team?

- Any of the signs or behaviors listed above
- Changes in food or fluid intake
- Decrease in urine output
- Change in frequency or type of bowel movements
- Depression
- Wandering
- Withdrawal from people or activities
- Any change in medications the team is unaware of

orig. 07 05, rev. 01 09, 07 13

What can be done for delirium?

Delirium is common at the end-of-life. It has many causes. The team will try to find out what is causing the delirium. The team will discuss treatment options with you. As a caregiver you may:

- Keep the patient safe
- Remind the patient who you are when you assist with caregiving. Tell them what you are going to do. For example, "I am going to help you get out of bed now"
- Offering support such as "I am right here with you"
- Try to maintain a routine and structure
- Avoid asking a lot of questions
- Provide a quiet, peaceful setting, without TV and loud noises
- Play the patient's favorite music
- Keep a nightlight on at night
- If starting a new medication, watch for improvement, worsening or side effects and report to healthcare provider

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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Core Curriculum for the Generalist Hospice and Palliative Nurse. Dubuque, IA: Kendall/Hunt Publishing Company; 2011.

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Hospice & Palliative Nurses Association
Advancing Expert Care in Serious Illness

PATIENT / FAMILY
TEACHING SHEET

Managing Depression

What is depression?

- A range of feelings that may include sadness, gloom, numbness, emptiness, helplessness and hopelessness
- Occurs frequently in chronic and terminal illness
- Symptoms are often the same as those of illness

What are the signs and symptoms of depression?

- Fatigue
- Sadness, depressed mood
- Loss or appetite with weight loss
- No interest or pleasure in daily activities
- Withdrawal from family and friends
- Sleep problems
- Feelings of worthlessness, hopelessness, guilt
- Difficulty focusing and thinking
- Thoughts of death or suicide
- Agitation or slowing down

What to report to the hospice/palliative care team?

- Any of the symptoms
- A known history of depression
- Any symptoms such as pain, nausea, difficulty breathing
- Change in medications the team may be unaware of

orig. 07 05, rev. 01 09. rev 07 13

What can be done for depression?

Depression may occur at the end-of-life. There is a wide range of intensity of depression. The team will help you sort out causes of depression. They will discuss treatment options with you.

You may:

- Optimize physical status with rest and nutrition
- Set small, realistic, achievable goals
- Utilize relaxation techniques
- Consider complementary therapies such as aromatherapy, art and music therapy

Your caregiver may:

- Keep you and your area safe
- Let you know that they will be there
- Allow you to express feelings
- Allow you to control as much as possible related to treatment decisions and activities

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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Hospice & Palliative Nurses Association
Advancing Expert Care in Serious Illness

PATIENT / FAMILY TEACHING SHEET

Managing Nausea and Vomiting

What is nausea and vomiting?

There are many different causes of nausea and vomiting that may be related to your illness or treatment. Your hospice and palliative care team will try to discover the underlying reason in order to offer treatment options.

- Nausea is an unpleasant feeling that may occur in the back of the throat or stomach prior to vomiting
- Vomiting is the emptying of stomach contents

What to report to the hospice/palliative care team?

- Amount and frequency of nausea and vomiting
- Description of vomited fluid
- Altered mental status

What can be done?

The good news is that there is much you, your caregiver and the hospice/palliative care team can do for nausea and vomiting. Discuss with your healthcare team which options are best for you. These may include:

- Record what causes you to feel nauseated or to vomit and what decreases the nausea and/or vomiting
- Sip carbonated drinks that have gone flat
- Drink sports drinks (such as Gatorade®) – with children use Pedialyte®
- Provide small amounts of salty foods (such as crackers, chicken broth)
- Provide foods as requested by patient in small frequent amounts as large meals may be overwhelming
- Provide frequent mouth care
- Try sips of water or ice chips before eating again
- Maintain a comfortable room temperature
- Increase air flow by opening a window or placing a small fan in the room
- Try alternative therapies such as massage, guided imagery, or progressive muscle relaxation
- Engage in relaxing activities that may distract from the nausea, such as listening to music, watching TV, working puzzles, sketching or drawing, reading, or yoga
- Use medications as ordered by your healthcare provider

orig. 08 08, rev. 05 11

- Avoid juices (such as cranberry, grape, apple)
- Avoid fried foods, milk products, or foods with strong smells
- Avoid strong odors such as perfume and deodorizers
- Avoid eating immediately after vomiting
- Avoid constipation

Contact your hospice/palliative care team if nausea/vomiting continues.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

References

Core Curriculum for the Generalist Hospice and Palliative Nurse. Dubuque, IA: Kendall/Hunt Publishing Company; 2010.

Ferrell B, Coyle N. *Textbook of Palliative Nursing.* 2nd Ed. New York, NY: Oxford University Press; 2010.

Approved by the HPNA Education Committee, August 2008, Revised by the Education Services Committee, May 2011

Managing Constipation Caused by Opioids

Constipation caused by opioids (pain medicine)

Constipation is the passage of hard, dry stools less often than the person's usual bowel pattern. Individuals and healthcare providers may differ in their thoughts of what is considered constipation. Frequency of bowel movements (BM's) is not the most critical factor. Comfort having BM's is the important factor. It varies how often a person has a BM. Normal BM's can range from 3 BM's per day to 3 per week. Opioids (such as morphine) are medications that are used for the relief of pain. Opioids also slow the movement of the bowel which leads to constipation. Constipation during opioid therapy is very common. A plan to prevent this should be started as soon as these medications are prescribed. Laxatives should be taken as regularly as the opioids. For example, if a person takes opioids daily, he/she should also take laxatives daily. Your hospice and palliative care team (your team) will discuss this with you.

What are the signs and symptoms?

- Less frequent stool, dry hard stools, straining during bowel movement
- Incomplete passage of stool
- Bloating and swelling of the abdomen
- Cramping, nausea, vomiting, reflux/heartburn
- Any of the above symptoms with small smeary or liquid stools (the liquid moves around constipated masses of stool and does not count as a BM)

What to report to the hospice/palliative care team?

Constipation may be embarrassing to discuss. However, it is very important for your care and comfort.

- Keep a record of your BM's. List the day and time of your BM. Describe what the stool looked like and if you had any problems during the BM
- Change in the frequency of bowel movements
- Change in stool: consistency of stool (hard, soft, liquid), smaller size, oozing liquid stool
- Urge but inability to pass stool or rectal fullness or pressure
- Change in the amount of gas passed rectally
- Constipation may worsen if you are not drinking enough liquids. If you are not able to drink enough fluids talk to your hospice and palliative team
- It is important to tell your team if you are taking any over the counter medications or if there have been any medication changes made since the last visit. Many medications can make constipation worse

orig. 03 08, rev. 05 12

- Abdominal symptoms (bloating/swelling, distention, cramping, nausea, vomiting, reflux/heartburn, gas)
- Problems with passing stool (straining, incomplete passage of stool or diarrhea, hemorrhoidal pain or bleeding)
- It may be helpful to keep a record. An example of a Bowel Movement Record is attached to this document and available from HPNA at http://www.hpna.org/DisplayPage.aspx?Title=Patient/Family%20Teaching%20Sheets select *Managing Constipation Caused by Opioids*

What can be done for opioid induced constipation?

A person taking opioids should have BM at least every 2-3 days. The stools should not be hard or cause strain. Comfort when having a BM is important.

- Stool softeners and laxatives are medications used for constipation. It is important to have stool softeners and laxatives prescribed at the same time the pain medication is prescribed. It may take a few changes to find the right combinations of medications that work best for you
- Drink 8 glasses of fluid per day if able
- Include natural fiber from fruits and vegetables in your diet
- Drink warm fluids with or after meals to stimulate the bowel
- Exercise if able. Walk or sit upright after meals. This helps with digestion
- "Train" your bowels by sitting on the toilet at the same time daily
- Do not fight the urge to have a BM even if in a public restroom
- Keep a record of your BM's. List the day and time of your BM. Describe what the stool looked like and if you had any problems during the BM

Conclusion

Managing constipation is key. A plan to prevent constipation caused by opioids (pain medication) should be started as soon as these medications are prescribed. It is important not to stop taking the pain medication because of the constipation. Talk with the health care team about what will work best for you.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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BOWEL MOVEMENT RECORD

DATE and TIME of BM	**CONSISTENCY of STOOL** Examples include; hard, soft, liquid	**ABDOMINAL SYMPTOMS** Examples include; bloating, distention, gas cramping, nausea, vomiting, reflux, heartburn	**PROBLEMS WITH PASSING STOOL** Examples include; straining, incomplete passage of stool, leakage of stool, diarrhea, hemorrhoidal pain or bleeding

QUESTIONS OR COMMENTS FOR THE HOSPICE AND PALLIATIVE HEALTH TEAM

orig. 01 06, rev. 07 09, rev 07 13

PATIENT / FAMILY TEACHING SHEET

Managing Pain

What is pain?

- It is what the individual says it is
- Hurting or discomfort
- A condition that can cause physical, emotional or spiritual distress and can contribute to financial stress
- An experience that can only be felt and described by the person with the pain
- Pain affects everyone involved
- Older adults may describe pain as aching, burning, gnawing, grabbing, being uncomfortable, soreness
- Children may express pain in different ways, such as they may sleep more, become irritable, or have other behavior changes. They may use words like oowie or boo-boo to describe pain
- Confused patients, those with cognitive impairment, or those that cannot speak for themselves may have behavior changes such as pacing, moaning, agitation, grimacing, and furrowed brow that can indicate pain

What to report to the hospice/palliative care team?

- How severe or intense the pain is. It can be reported as a number using 0 as no pain and 10 as the worst possible pain imaginable. Other ways of reporting pain are also available such as, mild to severe, using different types of pictures. Ask your nurse to tell you more about the options for reporting. There are also options for rating children’s pain.
- Where the pain is located
- If the pain keeps you from doing your usual activities
- What makes the pain worse
- What makes the pain better
- What does the pain feel like (burning, sharp, stabbing)
- Is the pain constant or does the pain come and go
- How well the pain medication is working
- How often you are taking pain medication
- Any side effects of the medication (common side effects include: constipation, nausea, vomiting, sleepiness, dizziness, itching)

orig. 01 06, rev. 07 09, rev 07 13

- Concerns about the medications, how to take them or how to administer them
- If you are becoming irritable from lack of sleep because of the pain

What can be done?

The good news is that there is much you, your caregiver, and the hospice and palliative care team can do for managing pain. They will try to find the reason for the pain and discuss treatment options with you. Medications are usually necessary to relieve pain – the nurse will give you information about the medicines, when to take them and what you need to know.

- It is important to take or administer the medicines as ordered
- Many side effects can be treated and/or may even stop after taking the medication for a few days
- Other things that can make the pain better are:
  - Relaxing activities such as listening to music, light massage, soaking in a tub of warm water, or guided imagery (picturing enjoyable and relaxing scenes to take one's mind off the pain)
  - Distracting activities such as watching TV, playing a game, or just thinking of other things
  - Heat or cold (such as a heating pad, warm compress, or ice pack)
  - Pleasant smells of certain plants or fragrances (aromatherapy) such as lavender, etc.
  - Storytelling, drawing
  - Deep breathing
- Ask your hospice and palliative care team to teach you how to use these ways of relieving the pain

Once medications are no longer needed your hospice and palliative care team will advise you on the proper disposal of medications.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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Advancing Expert Care in Serious Illness

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PATIENT / FAMILY TEACHING SHEET

Managing Restlessness

What is restlessness?

- An inability to rest, relax or concentrate
- Extreme restlessness is sometimes called agitation
- A condition that occurs in nearly half of all patients during the last 48 hours of life

What are signs of restlessness?

- Muscle twitching
- Moving around without a known reason
- Pulling at sheets, covers or clothing
- Trying to get out of bed for no known reason
- Fidgeting
- Sleeplessness
- Inability to get comfortable
- Grimacing

What to report to the hospice/palliative care team?

- Any of the signs or behaviors listed above
- Inability to administer medications by prescribed method
- Things that make the restlessness worse, for example: loud music
- Things that make the restlessness better, for example: soft music
- Concerns that you may have as a caregiver to cope
- Need for spiritual support
- Situations that might be unsafe

orig. 06 08, rev. 06 11

What can be done for restlessness?

The team will try to find the reason for the restlessness and talk with you about treatments.

Things you can do:

- Administer prescribed medications as ordered
- Offer frequent reassurance
- Offer relaxation activities, for example: play soothing music
- Keep things calm, for example: decrease numbers of visitors
- Read favorite stories, poems, etc. in a calm voice
- Hold the person's hand, give them a gentle massage
- Keep the person safe, for example: do not leave the person alone while restless and check frequently when calm
- Understand that restlessness may be a sign that the patient is close to death – let other family members know what is happening

Other HPNA Teaching Sheets on are available at www.HPNA.org.

Reference

Core Curriculum for the Generalist Hospice and Palliative Nurse. Dubuque, IA: Kendall/Hunt Publishing Company; 2010.

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**PATIENT / FAMILY
TEACHING SHEET**

Managing Shortness of Breath

What is shortness of breath (dyspnea)?

- A personal experience for each individual
- An uncomfortable feeling of having difficulty breathing
- Can be described as not getting enough air (a feeling that you cannot catch your breath, like the room is closing in or that there is not enough air in the room)

When should I seek advice about my shortness of breath?

- When it stops you from doing what you want to do
- When it causes you or your family fear, anxiety, nervousness or restlessness
- When it causes bluish discoloration of your face, ears, nose, fingers or toes

What can be done?

The good news is that there is much you, your caregiver and the hospice and palliative care team can do for shortness of breath. The team will always try to find out the cause and discuss treatment options with you and your family. Things that may be helpful:

- Sit in a chair or recliner
- Elevate your head on pillows when lying in bed
- Sit with your hands on your knees or on the side of the bed leaning over the bedside table
- Practice pursed lip breathing technique. Take slow, deep breaths, breathing in (inhale) through nose and then breathe out (exhale) slowly and gently through pursed lips (lips that are “puckered” as if you were going to whistle)
- Increase air movement by opening a window, using a fan or air conditioner. Apply a cool cloth to your head or neck
- Use oxygen as directed by your healthcare provider
- Take medication as directed by your doctor
- Keep your environment quiet to decrease feelings of anxiety
- Use relaxing activities such as prayer, medication, calming music, and massage
- Notify the team if your shortness of breath is not relieved or gets worse

orig. 01 06, rev. 08 09, rev 07 13

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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PATIENT / FAMILY TEACHING SHEET

Preparing the Children: Preschool ages 3-5

Adults sometimes feel that children are too fragile to face the reality of death, or too young to understand. Children experience the same emotions adults do; most are emotionally strong enough and want to know about death. The truth helps them understand what is real and what is not. It is important to remember that grieving is natural. Support for their unique grief processes helps children heal and learn to live with a painful loss. With help, a child may find grief a growing process. It is important to make sure that the help offered is age appropriate.

Age affects how children understand death – Preschool children ages 3-5 years

- May have some understanding about death, but may think it is reversible like he/she sees on cartoons
- May ask when a loved one will return, or may need the facts repeated
- May believe that his/her thoughts or feelings have power over others and may believe he/she caused a loved one’s illness or death
- Do not understand that every living thing will die and may question if other people or pets die

How to explain

- The person talking to the child should be someone the child knows and trusts and it should be done in a quiet, private place
- Tel the truth; explain what dead means. Keep it simple by saying the person’s “body stopped working” and the doctors could not fix it. Tell the child he/she will never see that person again except in his/her memory or pictures
- State the facts that the person “died/is dying” <u>not</u> that he/she “went/going away,” “Passed/ing to the other side,” or “went/going to sleep.” The child may expect the person to return or wake up
- Tell the child it is okay to cry or feel angry or sad. Acknowledge that it is a scary, confusing time. Allow him/her to see adults crying and express their emotions. Allow the child to ask questions

What can be done?

- Reassure the child that it was not his/her fault, that he/she will be cared for and is loved
- It may take some time for a child to react. Be present and attentive
- Allow the child to play and have fun
- Certain books may be a good tool to help the child become aware of his/her feelings and talk about them. Children may identify with a character in a book, learning they have similar feelings, which helps the healing process. Ask the nurse about books

Signs and symptoms of Grieving/Mourning

- Anxiety. The child may be clingy or demanding. He/she may loose his/her sense of security, or fear the loss of another loved one

- Sleep difficulty. This is common, especially if “sleep” was used to describe death. He/she may have nightmares
- Behavior changes “acting out.” The child may be angry at death, God, or other adults or himself/herself. He/she may feel responsible
- Withdrawal. The child may not want to talk about the dying loved one, hide in his/her room or behind furniture
- School problems. The child may have difficulty concentrating
- Physical complaints. The child may experience, such as a headache, stomach ache or similar symptoms as the person who is ill or died

What to report to the hospice/palliative care team?

- Any kind of extreme behavior

Should children visit the dying?

- Depends on the situation. If the child is old enough to understand what is happening and the dying person has played an important role in his or her life, then it may be good for both the child and the dying person
- The child needs to be prepared for what he/she will see and hear. A picture and description of equipment in the room may help
- May be useful to children, to help diminish the mystery of death
- May help the child develop more realistic ways of coping
- A child should never be forced to visit a dying person or go to a funeral, nor should he/she be made to feel guilty for not wanting to be involved

Should children attend funerals?

Yes, if a child wants to go and is old enough to understand the event. Rituals can be an important part of the grieving process. Prepare the child for the event by explaining what they will see and hear, especially if there will be a viewing. Give the child a choice, but try to understand the child’s reasons so you can address any fears or misconceptions and answer questions.

The grieving process is normal and the process helps both adults and children heal from their pain. If you have questions or concerns, please contact the hospice or palliative care team, a bereavement group, religious advisor, or a mental health professional. Your child and you may need support during a time of grief. Please don’t hesitate to ask for help.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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Preparing the Children: Preteens and Teens

Adults sometimes feel that children are too fragile to face the reality of death, or too young to understand. Children experience the same emotions adults do; most are emotionally strong enough and want to know about death. The truth helps them understand what is real and what is not. It is important to remember that grieving is natural. Support for their unique grief processes helps children heal and learn to live with a painful loss. With help, a child may find grief a growing process. It is important to make sure that the help offered is age appropriate.

Age affects how children understand death – Preteens and Teens ages 10 years and above

- May have developed an understanding of death; that death is final, but remains a mystery
- While understanding death, he/she still may be careless with their own health and safety because they have a feeling that it will never happen to him/her
- May want to talk about death and other abstract topics
- May begin to question the family faith and other beliefs

How to explain

- Should be done by a person they know and trust
- Know the facts and be honest. Make sure they understand that death could not be prevented, such as when a person dies of cancer
- Provide needed structure, support and guidance. He/she is no longer a child, but not yet an adult. Allow him/her to express anger or guilt. He/she may try to hide his/her feelings, so let him/her know his/her emotions are okay and normal. Maintain family closeness, but respect their privacy

Signs and symptoms of Grieving/Mourning

- Anger or guilt
- Withdrawal or attempts to hide their feelings
- Aggressive behavior
- Resistant to help and may react by trying to take care of others
- May have difficulty concentrating in school

What to report to the hospice/palliative care team?

- Any kind of extreme behavior

What can be done?

- Refer to professional counseling, if needed
- Access grief and bereavement support groups

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- Certain books may be a good tool to help the preteen/teen become aware of his/her feelings and talk about them. The preteen/teen may identify with a character in a book, learning they have similar feelings, which helps the healing process. Ask the nurse about books
- Allow him/her to participate in any family rituals such as funerals, wakes, and memorial services
- Allow him/her to speak to someone other than a parent about his/her feelings may be best. Encourage him/her to seek another trusted adult such as a counselor, teacher, pastor, or coach

Should children visit the dying?

- This depends on the situation. If the child is old enough to understand what is happening and the dying person has played an important role in his or her life, then it may be good for both the child and the dying person
- The preteen or teen needs to be prepared for what he/she will see and hear. A picture and description of the equipment in the room may help
- The preteen or teen should never be forced to visit a dying patient, go to a funeral or to the funeral home, nor should he/she be made to feel guilty for not wanting to be involved

Should children attend funerals?

Yes, if a child wants to go and is old enough to understand the event. Rituals can be an important part of the grieving process. Prepare the child for the event by explaining what they will see and hear, especially if there will be a viewing. Give the child a choice, but try to understand the child's reasons so you can address any fears or misconceptions and answer questions.

The grieving process is normal and the process helps both adults and children heal from their pain. If you have questions or concerns, please contact the hospice or palliative care team, a bereavement group, religious advisor, or a professional counselor.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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Preparing Children for Death: Ages 6-9 Years

How Should Adults Prepare Children Ages 6-9 for Death?

Adults sometimes feel children are too fragile or too young to face the reality of death. Children experience the same emotions adults do; most are emotionally strong enough and want to know about death. The truth helps them to understand what is real and what is not. Grieving is natural - at any age. Recognizing and supporting their unique grief processes helps children to grow emotionally and to heal as they learn to live with a painful loss. It is important that the help offered is age appropriate since age affects how children understand death. School-aged children 6-9 years:

- Are beginning to understand that death is final.
- May need more facts about death or how a loved one died, and may be curious about the physical details.

How to Explain Death and Dying

- The person talking to the child should be someone the child knows and trusts, and the conversation should happen in a quiet, private place.
- Tell the truth; explain what “dead” means. Keep it simple by saying the person’s “body stopped working,” and that the child will never see that person again except through memories or in photographs.
- State the facts. Say a person “died/is dying,” not that he/she “went/is going away,” “passed/is passing to the other side,” or “went/is going to sleep.” When these descriptions are used, the child may then expect the person to return or to wake up. Also, if the person died of illness, explain how the person was very, very sick so the child will not be scared when he/she gets a minor illness.
- Talk about emotions and feelings. Tell the child it is okay to cry or to feel angry or sad. Explain that it is a scary, confusing time. Allow the child to see adults crying, to express emotions and to ask questions.

Signs and Symptoms of Grieving/Mourning

- Anxiety – The child may be clingy or demanding, lose his/her sense of security or fear the loss of another loved one.
- Sleep difficulty – This is common, especially if the word “sleep” was used by someone to describe death. The child may even have nightmares.
- Behavior changes, such as “acting out” – The child may be angry at death, God, other adults or himself/herself. He/she may feel responsible.
- Withdrawal or attempts to hide feelings – The child may not want to talk about the dying loved one and may hide in his/her room.
- School/health problems – The child may have difficulty concentrating, or may experience headaches, stomach aches or similar symptoms as the person who is ill or has died.
- Denial – Refusing to admit the death happened, and fear that other loved ones will die, can also be symptoms.

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What to Report to the Hospice/Palliative Care Team?

- Any kind of extreme physical or emotional behavior should be reported.

Should Children Visit the Dying or Attend Funerals?

- Visitation depends on the situation. A visit may help the child by lessening the mystery of death. If the child is able to understand, and the dying person has played an important role in his/her life, then a visit may be good for both the child and the dying person.
- The child needs to be prepared for what he/she will see and hear. A picture and description of the equipment in the room may help.
- A visit may help the child to develop more realistic ways of coping with death. A child should never be forced to visit a dying patient, or go to a funeral or funeral home. No child should be made to feel guilty for not wanting to be involved.
- A child should attend a funeral if he/she wants to go and is old enough to understand the event. Rituals can be an important part of the grieving process. Explain what the child will see and hear, especially if there will be a viewing. Give the child a choice, and try to understand the child's reasons for wanting to attend. Be prepared to address any fears or misconceptions and answer questions.

What Else Can be Done to Help Children?

- Reassure the child the death was not his/her fault, and he/she will be loved and cared for.
- It may take some time for a child to react. Be present and attentive.
- Allow the child to play and have fun.
- Rituals are important at this stage and can help the situation to seem more real. Allow a child who is interested to participate in a funeral or memorial service.
- Certain books may help a child become aware of feelings and talk about them. If a child identifies with a character in a book who shares similar feelings about death and dying, it can help the healing process. Ask your nurse to recommend appropriate books.

The grieving process is normal, and mourning helps both adults and children heal from the pain that comes with loss. If you have questions or concerns, please contact the hospice or palliative care team, a bereavement group, a religious advisor or a professional counselor.

Other HPNA Teaching Sheets are available at www.goHPNA.org.

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PATIENT / FAMILY
TEACHING SHEET

Psychological Distress

What is psychological distress?

Uneasy feelings of anxiety or depression in response to physical, spiritual, or emotional demands – or a combination of multiple demands – that result in temporary or permanent harm

What are the signs and symptoms of psychological distress?

- Feelings of anxiety, sadness, anger. Wanting to be alone
- Feeling “out of control” or overwhelmed much of the time
- Difficulty coping with everyday problems
- Unable to talk about ways to solve problems or talk about fears
- Needing the help of others to make decisions
- Trouble sleeping
- Not taking care of self
- Looking sad, frowning. Crying easily. Loss of hope or sense of comfort
- Laughing at odd times
- Aches and pain. Feeling that your heart is racing
- Thoughts of suicide or hastening death
- Not wanting to follow the advice of the healthcare team

What to report to the hospice/palliative care team?

- Any signs of behaviors listed above
- New onset of reckless behavior. Talking or thinking about suicide
- Firearms in home. Hoarding or stockpiling medications
- Seeing images or hearing voices not seen or heard by others
- History of psychiatric illness or history of use of medications taken for depression, anxiety, schizophrenia, dementia, or bipolar disorder
- Lack of interest in self or life in general
- If you experience a new problem, or if a current problem is getting worse and the present medication does not seem to be working
- Side effects of medications

orig. 06 08, rev. 06 11

What can be done for psychological distress?

Psychological distress is common with terminal diseases, especially if physical symptoms are present. Your healthcare team wants you to be physically comfortable. There is a direct link between how one feels physically and how one feels psychologically and emotionally.

Patients and Family

- Do not feel that you are bothering your healthcare team by asking questions
- Asking questions means you care

Patient

- You may not feel up to talking with many people. You may want to have one person to talk to whom you trust
- Try to have a daily routine including a regular sleep schedule
- Eat a balanced diet and exercise as you are able
- Avoid alcohol and non-prescribed drugs and herbal remedies
- Ask for and accept assistance from your team, including: family, friends, nurses, physicians, nursing assistants, social workers, chaplain

Family

- Provide calm, relaxing setting
- Be flexible. The patient may want to talk one day. The next he/she may need quiet and calm
- Be willing to be with them without having to “do” something
- If needed, help with medications. Report any medication side effects or changes in behavior
- Treat the patient with dignity and respect
- Don’t be afraid to ask for help. Do not be hard on yourself with comments like “I should have done this or that” or “I should have known that”
- As much as you can, enjoy this time together and look for ways to make memories

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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Hospice & Palliative Nurses Association
Advancing Expert Care in Serious Illness

PATIENT / FAMILY
TEACHING SHEET

Self-Care for the Caregiver

Why it is important?

Caregivers are very important to the care of persons with serious or life-threatening illnesses. More than 70% of people who die have had care from family caregivers. Caring for a loved one who is seriously ill can be hard work and can be very stressful. Your ability to do this work improves when you take time to take care of yourself. Self-care is about meeting your own needs so you are able to be an effective caregiver. It is important to be well rested to provide the best care. Some helpful suggestions include the following.

Physical needs

- Remember to take care of your own health.
- Keep your own medical, dental, and therapy appointments.
- Schedule time to eat: have at least 3 healthy but simple meals a day.
- Learn to make meals in advance. Ask friends/family if they will help making meals.
- Ask how best to provide care to your loved one and prevent injuring yourself.
- Take time to rest, especially if sleeping has become hard for your.
- Avoid/limit the use of tobacco and alcohol as they make it difficult to fall asleep.
- Try to get exercise during the day.
- Take time for yourself. This can include reading, listening to music, taking a bath, going for a walk, praying, gardening, and other activities you enjoy.

Communication needs

- Tell people about your worries and concerns. These people may be family, friends, or some of the healthcare providers working with you to help care for your loved one.
- Stay informed! Ask what signs and symptoms the person you are caring for may have so that you are prepared to deal with them.
- Get organized and set realistic goals for your day. Be flexible. Set limits.
- Ask others to help with whatever you or your loved one needs.
- Stay informed about the hospice visits and any changes in the schedule.

orig. 03 07 rev. 01 09 rev. 10 13

Emotional/spiritual needs

- Continue relationships with family and friends to avoid feeling alone. If it is difficult for you to get out, ask people to come visit. Let people take care of you and allow your loved one to say thank you for all you do.
- Work with your team to provide time to get out of the home to enjoy social activities or attend support groups. When possible, keep doing favorite activities. Try to keep things simple.
- Talk about what is happening to your loved one. Expect to feel angry, stressed, or frustrated at times. These are normal responses.
- Tell yourself every day you are doing a great job. Breathe and laugh
- Let your hospice/palliative care team know if you are feeling overwhelmed. Your team has resources to help.
- Attend to your spiritual needs by calling or visiting your clergy, church or synagogue.
- Have your own "special space." This can be your room, a chair, a table, etc. Someplace that is yours where you can go unwind.
- Take short breaks outside the house, even for a few minutes.
- Seek additional professional help if you are feeling scared, helpless, lost, or depressed.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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Hospice & Palliative Nurses Association
Advancing Expert Care in Serious Illness

PATIENT / FAMILY TEACHING SHEET

Skin Care

Why it is important?

Care of the skin is an important part of the overall care. The skin is the largest organ of the body. It is the immune system's first line of defense against infection.

How can I keep the skin healthy?

- Healthy skin needs to be cleaned and well hydrated.
- Wash with warm water and mild soap.
- Avoid friction or rubbing.
- Clean skin after each soiling.
- Use alcohol-free lotions on dry skin for moisturizing.
- Do not massage reddened areas.

What can be done to prevent damage to the skin?

- Encourage the person to be out of bed as tolerated.
- Avoid having person sit up straight in bed longer than necessary. This puts pressure on the buttocks and sacrum.
- Raise heels off of the bed by placing pillows under calves and knees for support.
- Change the bedbound person's position at least every two hours; one hour if in a chair.
- Remind the person to shift their own weight, if possible, every 15 minutes.
- Ask your team to show you how to use "draw" or "pull" sheets to move the person, avoiding friction from sheets.
- Keep the person's skin clean and dry.

What to report to the hospice/palliative care team

- Reddened areas that do not fade.
- Open areas or blisters on the skin.
- Any changes in the ability to turn or change the person's position. If it becomes difficult for the person to change position because of weakness or pain.

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The team can advise you on special pads and mattress overlays to help prevent skin breakdown. Nutrition is important but sometimes food may overwhelm the sick person. Offer protein-rich drinks and snacks during the day as person tolerated.

Even though attentive care is provided, skin can break down because of the physical changes that occur at end of life. Skin breakdown can result from lying in bed much of the time. Other medical issues may prevent or delay healing. It is important to report any changes, redness or skin breakdown to the nurse.

The person's comfort is the goal of care.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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Hospice & Palliative Nurses Association
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PATIENT / FAMILY TEACHING SHEET

Social Distress

What is social distress?

Social distress is a change in a person's social life (roles, relationships, sense of belonging, sexual function and appearance which causes a suffering of mind or body.

What are the signs and symptoms of social distress?

- Feelings of :
  - Being lonely and/or feeling alone.
  - Not being able to carry out personal roles, such as spouse/partner, parent, or friend.
  - Not being able to do your job.
  - Shame of failure regarding not being able to have sex or lacking an interest in sex. This could be due to illness and related issues.
  - Fear about financial concerns.
  - Fear about being a burden to those providing care.
- Not wanting to receive company or visitors. This may include even close friends or relatives. It could be due to the effects of your illness on your appearance.

What to report to the hospice/palliative care team?

- Any signs of behaviors listed above.
- Any thoughts about suicide.
- Prior history of social distress.
- No interest in self and life in general.
- *Unusual* anger or lashing out. The person may not understand the reason for the anger or how to cope.
- Any change that concerns you.

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What can be done for social distress?

Social distress is common with terminal illnesses. Not everyone experiences it the same way.

Patients and Family

- Do not feel you are bothering the hospice and palliative care team by asking questions.

Patient

- It is very important to have at least one person with whom you trust to talk with and share your thoughts and feelings.
- Do not be hard on yourself for not feeling very social.
- Allow yourself to be angry. Tell others about your anger.
- Be sure to take your medications as prescribed.
- It is okay to want quiet time. Consider using this time to reflect, record memories and future messages for your family.

Family

- Provide calm, relaxing setting.
- Treat the patient with dignity and respect.
- Be willing to be present. Provide support.
- Be willing to listen and reminisce.
- Enjoy the time together, look for ways to make memories.
- Report any medication side effects or behavior that is out of character.
- Support any desire to stay in touch with friends and family.
- Encourage short periods of time for visitors during the day.
- Try not to let the patient become secluded.

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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PATIENT / FAMILY TEACHING SHEET

Spiritual Distress

What is spiritual distress?

Spiritual distress is a disruption in a person's belief or value system. It may occur when a person is unable to find sources of meaning, hope, love, comfort, strength, and connection in life or when conflict occurs between his/her beliefs and what is happening in their life. It may affect his or her entire being. Something in a person's past can also be a cause of distress.

What are the signs and symptoms of spiritual distress?

- Sadness, anger, despair, depression, anxiety.
- Questions the meaning of life. Questions the meaning of suffering.
- Asks why this is happening, "Why now?", "Why me?"
- Afraid to fall asleep.
- Questions his/her belief system.
- Feels a sense of emptiness, loss of direction, abandonment.
- Talks about feelings of being left or forgotten by God/higher power.
- Seeks spiritual help or guidance.
- Pain and other physical symptoms may be expressions of spiritual distress.

What to report to the hospice/palliative care team?

- Signs of behaviors listed above.
- Side effects of medications.
- Behaviors that seem out of character.
- Symptoms that are getting worse.
- Talk about suicide, ending it all, asking for help to die.
- Known history of spiritual distress.
- Not caring about self and life in general.
- Sudden rejection or neglect of previous practices or beliefs.

What can be done for spiritual distress?

Spiritual distress is common with terminal illnesses. Not everyone experiences it the same way or to the same degree.

Patients and Family

- Do not feel you are bothering the hospice/palliative care team by asking questions.
- Look for ways to keep and honor desired rituals and ways of life.

Patient

- Remember, not everyone has spiritual distress.
- Have at least one person to talk with whom you trust about your concerns, fears, or anger.
- Do not be hard on yourself for not feeling very spiritual.
- Listening to devotional recordings may offer comfort.
- Listening to instrumental music may be soothing.
- Allow someone to pray with/for you. Meditation may be helpful.
- Write, paint, or draw your feelings.
- Take your medication as prescribed.
- Forgive yourself, forgive others, and forgive God/higher power.
- Say thank you.

Family

- Provide a calm, relaxing setting.
- Treat the person with dignity and respect.
- Be willing to be present. Provide support.
- Be willing to listen and reminisce.
- Enjoy the time together, look for ways to make memories.
- If asked, be open to contacting a spiritual leader (minister, rabbi, priest).

Other HPNA Teaching Sheets on are available at www.HPNA.org.

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