

### **Abstract**

Patients with pancreatic cancer and their families struggle with physical and emotional issues. They could benefit from palliative care services, but may not have access to them. The Internet has become an important source of health information and a link between patients, families and health care providers.

The purpose of this capstone project was to 1) determine if patients and their families would use a Web page where they could access a palliative care nurse practitioner (PCNP); 2) to identify the palliative care needs of the patients and families who accessed the PCNP; and 3) to determine the helpfulness of the Web page. Participants were recruited to the PCNP Web page from the Johns Hopkins Pancreatic Cancer Research Center's (JHPCRC) Web site. A mixed method design was used to determine 1) the volume of participation with the PCNP Web page, 2) patient and family member needs, and 3) the usefulness of the Web page. Participants could post their questions to the public comments section of the PCNP Web or send the PCNP a private email. There also was a link to an online survey to gather demographic and evaluative information.

The PCNP Web page was visited 650 times by 395 unique individuals over an 8-week period. Participants spent an average of 4 minutes and 4 seconds on the PCNP Web page. Half, 49%, came from a link posted on the discussion board of the JHPCRC Web site. Forty-eight participants posted a total of 55 questions or sent individual emails to the PCNP. The majority were from female family members of patients with pancreatic cancer. The majority of questions (66%) fell into one of the eight domains of palliative care. Of these, most of the questions, 42%, asked about physical aspects of pancreatic cancer with the next largest domain, 11%, being psychological concerns about the illness and the risks of developing it. The other third of questions had to do with non-palliative aspects of pancreatic cancer and its treatment. Twenty

participants (5% of total visitors) completed the online survey. Most survey respondents were female, family members, middle-aged, white, and college-educated. Although statistical significance was not achieved, most survey respondents found the PCNP website helpful. It was considered easy to use and participants found information and support there and recommended that the PCNP page should be an on-going resource.

Access to a PCNP is an important resource for patients with pancreatic cancer and their family members. The Internet can be used to offer information, support and advice to patients and families dealing with a life-threatening illness.

RUNNING HEAD: Palliative care online

Use and assessment of a Palliative Care Nurse Practitioner on a Pancreatic Cancer Web Site

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## **Section One**

### **Statement of the Problem**

The problem is that patients with pancreatic cancer and their families could benefit from palliative care services, but may not have access to them. The barriers include lack of referrals, awareness, or service availability. When they come to the Johns Hopkins Pancreatic Cancer Research Center (JHPCRC) Web site, they do not find palliative care listed as an option. On the site's discussion board they find support from other patients and families, but professional healthcare providers do not monitor this board, which means information there may or may not be appropriate or accurate (See Appendix A for PICO outline).

### **Background/ Data Supporting Existence of the Problem**

Pancreatic cancer is the fourth leading cause of cancer deaths in the U.S. (American Cancer Society, 2008). In 2008, 37,680 Americans were diagnosed with pancreatic cancer and 34,290 died from it (American Cancer Society, 2008). The mortality is high with a five-year survival of only 5% (American Cancer Society, 2008). Pancreatic cancer is typically diagnosed at a late stage and is often complicated by vague symptoms easily attributed to other medical problems (Brescia, 2004). Routine examination of the pancreas is not possible as it is not anatomically accessible (Brescia, 2004). Screening is not an option as "there are no clear-cut high-risk populations to follow, even if effective screening procedures were available" (Brescia, 2004, p. 39).

Treatment options include surgery, chemotherapy and radiation. Surgery offers the only possible cure and, when performed at experienced medical institutions early in the disease, can provide a 40% five-year survival rate (Sohn et al., 2000). For those whose cancer is not surgically resectable, treatment options include chemotherapy and radiation. However, the disease "remains a chemoresistant tumor" (el-Kamar, Grossbard, & Kozuch, 2003, p. 18). As a

result, only 24% of patients diagnosed with pancreatic cancer will be alive a year later and almost 100% will eventually die of metastatic complications (American Cancer Society, 2008; Coleman et al., 2005). “Median survival for all patients is only six months” (Thomson, Banting, & Gibbs, 2006, p. 213). For most, pancreatic cancer is a terminal illness with a short duration. Patients and families struggle with its physical, emotional, and existential consequences.

Most pancreatic cancer patients are candidates for palliative care (Fazal, 2007). Palliative care is an emerging field that focuses on the needs of patients and families with serious illness. It uses an interdisciplinary approach that addresses issues in physical, emotional, psychological and spiritual domains to improve quality of life (National Consensus Project, 2009). Many healthcare providers equate palliative care with hospice (Snow et al., 2009), but palliative care can be provided at any point in an illness trajectory and in addition to any curative treatment (See Figure 1).

There are several barriers to accessing palliative care. First, many providers do not suggest these services while patients pursue aggressive treatment (Snow, 2009). Also, palliative care services are not yet widely available geographically or outside of hospitals (Goldsmith, Dietrich, Du, & Morrison, 2008). Finally, many patients and families are unaware of palliative care (Running, Shumaker, Clark, Dunaway, & Tolle, 2009). Therefore, those who could benefit from these services may not receive them. Some of these barriers could be overcome with the use of computer technology.

It is estimated that 74.4% of adults in North America are users of the World Wide Web ("Internet World Stats", 2009). This is up from only 14% of adults in 1995 ("Pew Internet Project Data Memo", 2009). For those seeking information on health, “the Internet has become a beacon of information and support” (Walther, Pingree, Hawkins, & Buller, 2005). The Pew Internet and American Life Project, 2009, estimates that 75% of online adults in America have used the

Internet to find health information (Pew Internet & American Life Project, 2009). For support, a growing phenomenon on the Internet is that of social networks. It is estimated that over a third (35%) of all adults online have a profile on social network sites (Lenhart, 2009). “As many as one in four disease information seekers join online discussion groups” (Meier, Lyons, Frydman, Forlenza, & Rimer, 2007, p. 2) and 33% of those searching for health information online use social media resources (“How America Searches: Health and Wellness,” 2008).

An additional feature of the Internet is the opportunity to interact with healthcare professionals. The use of online health experts has been studied since the 1990s. A range of studies confirm the effectiveness of such providers at reducing symptoms of complicated grief (Wagner, Knaevelsrud, & Maercker, 2006, 2007; Wagner & Maercker, 2007, 2008), depression (Christensen, Griffiths, & Jorm, 2004; Christensen, Griffiths, & Korten, 2002; Warmerdam, van Straten, & Cuijpers, 2007), anxiety (Reger & Gahm, 2009), emotional distress (Barak & Bloch, 2006), and pain (Lorig et al., 2002). In addition, there is a body of evidence confirming improved social and informational support from comprehensive programs for cancer patients that involve online providers (Gustafson et al., 2001; Gustafson et al., 2002; Shaw et al., 2007).

People newly diagnosed with pancreatic cancer and their families go to the Internet seeking information (Coleman et al., 2005). This is because pancreatic cancer is relatively rare. It “represents only 2% of new cancer diagnoses” (Brescia, 2004, p. 39). Thus, patients may not personally know someone with this illness. The Johns Hopkins Pancreatic Cancer Research Center (JHPCRC) has a public Web site that is regularly listed as one of the top unsponsored Google sites when one searches under “pancreatic cancer”. Johns Hopkins is a leading pancreatic cancer center and performs more pancreaticoduodenectomies (Whipple procedures) than any other U.S. center (“Our pledge to you,” No date). The JHPCRC Web site provides detailed information about pancreatic cancer and its various treatment options, including clinical trials.

For support, the Web site has an unmonitored discussion board that receives dozens of messages a day. A 2005 study of 600 messages on that discussion board suggested the need for more information regarding pain management and care giving at the end of life (Coleman et al., 2005). However, there is no specific information about palliative care on the Web site other than a brief section on pain management and a link to a hospice site. Therefore, people coming to the JHPCRC Web site do not learn of palliative care per se as a treatment modality.

### **Significance of the Project**

Patients with pancreatic cancer and their families need palliative care, and they use the Internet. This project is unique in that it explores how to bring those two factors together. Use of the Internet has burgeoned in the past 15 years, and it represents a new and increasingly prevalent modality for providing health information to the public. It can also provide aspects of palliative care to people who need it, regardless of their location or the stage of their disease, and provide it in a place where they are already going for information and support. By choosing the Internet, patients and families with pancreatic cancer can improve their understanding of the illness, their options for treating it, and also receive support and reassurance during a very difficult illness. This could overcome access barriers and broaden palliative care services and serve as a template for providing access to palliative care for those with other life-limiting conditions.

### **Purpose of the Project and Objectives**

The overall purpose of this project was 1) to determine if patients and their families would use a Web page where they could access a palliative care nurse practitioner (PCNP); 2) to identify the palliative care needs of the patients and families who accessed that PCNP Web page; and 3) to determine the helpfulness of the Web page. The objectives were to identify what the palliative care needs of patients and families posting to a PCNP on the JHPCRC Web site are

and what is the feedback about the online interaction with the PCNP. It was anticipated that people on the pancreatic cancer Web site would come to the PCNP Web page and find it helpful. Regarding the nature of the questions/emails, it was anticipated that many would be about pain and end-of-life issues and come predominantly from family members based on previous research (Coleman et al., 2005).

### **Theoretical Framework**

The theoretical framework for the project is the National Consensus Project's (NCP's) palliative care domains (NCP, 2004). The NCP was established in 2001. Representatives from the five leading palliative care organizations including The American Academy of Hospice and Palliative Medicine, The Center to Advance Palliative Care, The Hospice and Palliative Nurses Association, Lasting Acts Partnership, and the National Hospice and Palliative Care Organization met to "discuss the standardization of palliative care with the goal of improving the quality of care" (NCP, 2004, p. 2). The representatives agreed to the following goals:

- To build national consensus surrounding the definition, philosophy, and principles of palliative care through an open, interactive, and inclusive process, inviting an array of professionals, organizations, and consumers involved in, affected by, and benefiting from palliative care.
- Create voluntary, evidence-based, consensus Clinical Practice Guidelines for Quality Palliative Care, providing consistent and high quality services for patients and their families.
- Ensure broad dissemination of the Clinical Practice Guidelines for Quality Palliative Care to support and inspire future programs to develop clinical services of consistent and measurably high quality.
- Promote formal recognition, stable reimbursement structures, and accreditation

initiatives in palliative care (NCP, 2004, p. 4).

Over 200 recognized palliative care experts from various disciplines and organizations gave input to the NCP's process (Ferrell, 2005). Through a rigorous collaborative effort, eight domains were identified and confirmed (NCP, 2004). They were based on evidence from a comprehensive literature review and the consensus of the palliative care experts/leaders. The eight domains cover the range of the multidimensional aspects of palliative care. They are: 1) structure and processes of care; 2) physical aspects of care; 3) psychological and psychiatric aspects of care; 4) social aspects of care; 5) spiritual, religious, and existential aspects of care; 6) cultural aspects of care; 7) the imminently dying patient; and 8) ethical and legal aspects of care (NCP, 2004). They are used widely in palliative care curricula and program development and evaluation.

**Domain 1: Structure and processes of care.** Since palliative care, as an organized system for delivering care is relatively new, systems must be established for its implementation and growth. A key aspect of any palliative care system is that it be interdisciplinary. This typically involves a combination of resources from disciplines like nursing, medicine, social work, chaplaincy, etc. Links with hospice organizations are important to provide a smooth transition to hospice services when appropriate.

**Domain 2: Physical aspects of care.** This domain focuses on physical concerns. In addition to symptoms from the illness, there can be side effects from treatments patients may be getting for their disease. The role of palliative care is to help present symptom management and treatment options so that patients and families can make informed choices. Also, palliative care educates and supports the family so that they can help provide safe and appropriate comfort measures to patients.

**Domain 3: Psychological and psychiatric aspects of care.** This domain deals with the

emotional issues related to having a life-threatening illness. Such issues affect not only patients but also family. Palliative care includes assessment and management of these concerns including nonpharmacologic and complementary therapies.

**Domain 4: Social aspects of care.** This domain recognizes that serious illness affects the patient, the family, and the community. Palliative care treats the patient and the family as the unit of care. In addition to assessing physical and psychological issues, palliative care includes a social assessment.

**Domain 5: Spiritual, religious and existential aspects of care.** These aspects become increasingly important during a life-threatening illness. Patients and families struggle to understand what is happening and why. Terminal illness can cause people to question their faith, the meaning of life, or their purpose. Palliative care is attentive to spiritual care needs and concerns. People involved with illness also have the need for hope. Palliative care recognizes that there is always something to hope for, even though a cure might not be possible.

**Domain 6: Cultural aspects of care.** This domain recognizes the need to adapt any care to accommodate diverse cultures. At such a time, it is important to recognize and respect cultural practices so as to allow patients and families to be as comfortable as possible.

**Domain 7: Care of the imminently dying patient.** This refers to care provided in the final days or hours of a patient's life. Families often have little experience with the dying process since 75% of deaths in the U.S. occur in institutions (Gruneir et al., 2007). As a result families are often unaware of its signs. Related to this, palliative care also tries to offer patients and families a range of options for end-of-life care, including hospice.

**Domain 8: Ethical and legal aspects of care.** This domain addresses issues around treatment choices, medical decision-making, the use of life-support, and advance care planning. Palliative care seeks to respect patient and family goals in regard to preferences and choices for

medical treatment. Families are to be supported, regardless of their decision, as long as it is made in the patient's best interest. The advance care process is encouraged, as is confirming goals of care, to insure that the patient's wishes can be honored. This can be challenging given most Americans do not have advance directive documents (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007) and many are reluctant to discuss or plan for death (Carrese, Mullaney, Faden, & Finucane, 2002).

## Capstone Report Section Two

### Review of the Literature/Evidence

This section will discuss palliative care in more detail including the role of the advanced practice nurse. It will then review recent developments in Internet and online technology as they relate to health and cancer care. Online interactivity will be explored, particularly interaction with remote healthcare providers. The literature about such providers will be detailed focusing on studies related to aspects of palliative care.

**Palliative care.** The National Consensus Project (NCP) defines palliative care as: Both a philosophy of care and an organized, highly structured system for delivering care. The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care (National Consensus Project, 2009, p. 12).

The palliative care field developed over the past 20 years in response to the growth of chronic disease as the leading cause of death in the U.S. (Morrison & Meier, 2004). It has its roots in the hospice movement (Meier, Brunnhuber, Nash, Weissman, & Woodcock, 2008), which views death as a natural event that can be a time of growth with the right planning and preparation (Weggel, 1997). Palliative care was also spurred by several publications. The first was the landmark SUPPORT study. This trial, published in the Journal of the American Medical Association in 1995, confirmed problems experienced by seriously ill and dying patients in

American hospitals. Specifically, up to 50% of patients who died in the hospital experienced moderate to severe pain at least half the time (SUPPORT, 1995). Only 47% of physicians knew when their patients preferred to avoid CPR and 46% of do-not-resuscitate (DNR) orders were written within 2 days of death (SUPPORT, 1995).

Motivated in part by the SUPPORT study, the Institute of Medicine issued a report calling for improvements in end-of-life care (Field & Cassel, 1997). This report stressed four themes:

- Too many dying people suffer from pain and other distress that clinician could prevent or relieve with existing knowledge and therapies.
- Significant organizational, economic, legal, and educational impediments to good care can be identified and, in varying degrees, remedied.
- Important gaps in scientific knowledge about the end of life need serious attention from biomedical, social science, and health services researchers.
- Strengthening accountability for the quality of care at the end of life will require better data and tools for evaluating the outcomes important to patients and families (Field & Cassel, 1997, p. 2).

An important white paper by the RAND Corporation in 2003 focused on serious chronic illness among the elderly (Lynn & Adamson, 2003). It outlined the tendency to treat end-stage chronic illness with aggressive, and expensive, medical care. The report went on to point out that, at the current rate, there would be inadequate resources to do so for the baby boomer generation and recommended that healthcare policy be substantially reformed to deliver and finance quality end-of-life care (Lynn & Adamson, 2003).

Funding from organizations like the Robert Wood Johnson Foundation and the Soros Project on Death in America supported the development of national palliative care organizations

and a growing body of research. Today palliative care is a certified medical and nursing subspecialty whose aim “is to relieve suffering and improve the quality of life for patients with advanced illnesses and their families. It is based on an interdisciplinary approach that is offered simultaneously with other appropriate medical treatments and involves close attention to the emotional, spiritual, and practical needs and goals of patients and of the people who are close to them” (Morrison & Meier, 2004, pp. 2583-2584).

Palliative care is now available in most large hospitals. Specifically, 75.4% of those with more than 300 beds (Goldsmith et al., 2008) have palliative care services while only 20.1% of those with fewer than 50 beds do (Goldsmith et al., 2008). It is also not generally available in outpatient settings, long-term care facilities, or the home (Goldsmith et al., 2008). However, there are efforts to extend it to these settings (Center to Advance Palliative Care, 2009).

Wherever it is provided, the process is the same:

Palliative care begins with establishing the goals of care. Outlining realistic and attainable goals assumes an increased importance in the setting of advanced disease, in which treatments intended to cure the disease and prolong life may be more burdensome than beneficial. Whereas the goal for some patients may be to prolong life at any cost, studies suggest that what most seriously ill patients want is to have their pain and other symptoms relieved, improve their quality of life, avoid being a burden to their family, have a closer relationship with loved ones, and maintain a sense of control” (Morrison & Meier, 2004, p. 2589).

Paralleling the growth of palliative care as a medical specialty is the development of palliative nursing. The Hospice and Palliative Nurses Association (HPNA) was incorporated in 1987 as the Hospice Nurses Association and then added “Palliative” to the name in 1998. It supports nurses in both hospice and palliative care through education, certification, and

advocacy. The organization's position statement on the value of the professional nurse in palliative care states, "when faced with a serious illness, people turn to the professional nurse for education, support, and guidance. Nurses are intimately involved in all aspect of palliative care...they are the primary team members who coordinate, assess, direct, and evaluate patient care needs that arise during the illness experience" (HPNA, 2008, p. 1). Nurses play a critical role in caring for patients at the end of life. This is because "the care of the dying is essentially a nursing concern rather than a medical problem" (Thornburg, Schim, Paige, & Grubaugh, 2008, p. 383).

**Advanced practice nursing and palliative care.** In the last 25 years, the role of the advanced practice nurse (APN) has also grown. HPNA (2006) defines an APN as "a nurse who has earned a graduate level degree in nursing and is prepared to exercise independent judgment, synthesize complex assessment data, initiate care plans and treatment regimens and to evaluate health care environments. The APN demonstrates advanced specialized clinical knowledge and skills" (HPNA, 2006, p. 3). This description is similar to that of the American Nurses Association's (2004): "the APN integrates education, research, management, leadership and consultation into clinical roles and they function in collegial relationships with nursing peers and other professionals and individuals who influence the environment"(ANA, 2004, p. 1). Nurse practitioners (NP), one of the four types of APNs, are specifically trained to "perform comprehensive physical examinations, diagnose, interpret, prescribe, and make appropriate referrals and follow-up" (Kuebler, 2003, p. 708). NPs can be certified in various specialties and there is a certification for an Advance Practice Hospice and Palliative Care Nurse (ACHPN) by the National Board for Certification of Hospice and Palliative Nurses (NBCHPN). This certification is recognized by the Centers for Medicare & Medicaid Services (CMS) and provides "a national standard of requisite knowledge ... thereby assuring the consumer, the employer, and

members of the health profession in the recognition of the certified hospice and palliative caregiver” (HPNA, 2009, p. 2). The PCNP for this project is certified as both an ACHPN and as an acute care nurse practitioner.

The essential skills for a palliative care nurse practitioner are “effective communication, informed decision making, competent management of complications, symptom control, psychological care, care of the dying, and coordination of care” (Kuebler, 2003, p. 708). NPs work well in teams as they are “complementary to, rather than competitive with, the physician” (Coyne, 2003, p. 769). If a team or other multidisciplinary resources are not available, a nurse practitioner is the most appropriate single palliative care provider (Meier & Beresford, 2006). This is because of the combination of nursing’s holistic orientation, which includes a focus on physical, psychosocial, emotional, and spiritual issues.

APNs have a specific role in palliative care delivered to oncology patients. The principles of palliative care are particularly complex when applied to oncology patients. “Oncology patients in need of palliative care bring complex medical problems necessitating both expert clinical skills and expert system skills to guide them through the healthcare system” (Skalla, 2006, p. 158). Refer to Appendix B for a thorough list of nurse practitioner competencies for palliative care of oncology patients. Two studies show the benefits of APNs at improving outcomes for breast and cancer patients. One done in 2000 was a randomized control trial (RCT) involving 210 women newly diagnosed with breast cancer (Ritz et al., 2000). The control group received standard medical care while the intervention group received that and APN care. The APN care consisted of meeting with an APN within two weeks of diagnosis to receive information on breast cancer including what to expect from consultations with providers, decision-making support, and support via presence (Ritz et al., 2000). Patients met with APNs at subsequent clinic visits and also had access by phone and through home visits. Longitudinal surveys

measured quality of life via the Mishel Uncertainty in Illness Scale (MUIS), the Profile of Mood States (POMS), and the Functional Assessment of Cancer Therapy (FACT-B) (Ritz et al., 2000). Results showed a significant decrease in uncertainty among the intervention group vs. baseline, but no significant changes on the POMS or FACT-B (Ritz et al., 2000). The MUIS improvement was most significant within the first six months after diagnosis and the study concluded that APN interventions could be particularly helpful during that timeframe (Ritz et al., 2000).

The other study was a descriptive one of an APN-developed program to facilitate and increase breast and cervical cancer screening in a rural area (Schulz, Ludwick, Cukr, & Kelly, 2002). On screening days in 1996 and 1997, 20% and 23% of the targeted number of women in the county were screened (Schulz et al., 2002). Just under half of the women screened, 45.3%, needed further follow-up for breast and or cervical cancer abnormalities and/or additional health issues such as elevated blood pressure, glucose, weight, and perimenopausal issues (Schulz et al., 2002). The screening program was deemed a success and half of the women who had previously stated they had no regular health care provider subsequently identified the APN clinic as their regular source of care (Schulz et al., 2002).

An RCT conducted among elderly post-operative patients with cancer used APNs to do home visits and telephone follow-ups (McCorkle et al., 2000). The objective was to measure length of survival for these patients as compared to usual follow up care in an ambulatory setting. A total of 375 patients aged 60+ with newly diagnosed solid cancers that had been treated surgically were enrolled. The intervention was a standardized protocol that involved assessment and management of post-operative guidelines, instructional content, and scheduled contacts. APNs made three home visits and five telephone contacts over a four-week period. The intervention also included assessment, education and skills training for the family. The intervention group had longer survival over the 44-month follow up period with only 22% dying

vs. 28% in the matched control group. The longer survival was particularly true for late stage patients, who had a two-year survival of 67% compared to 40% among the control. This study noted that it was the first empirical study of post-operative cancer patients linked to a home care intervention delivered by APNs that showed improved survival. An additional APN study of palliative care provided to patients with advanced cancer over the phone (Bakitas et al., 2009) is summarized in the telemedicine section.

**Internet technology.** The Pew Research Center estimates that 74% of all American adults go online (Pew Internet & American Life Project, 2009). This ranges from a low of 31% for those aged 73 and older, up to 87% for those aged 18-32 (Pew Internet & American Life Project, 2009). The digital divide is also narrowing between racial and socioeconomic groups. According to the most recent data, the Internet is used by 77% of Caucasians, 64% of African Americans, and 58% of Hispanics (Pew Internet, 2008). By geography, 71% of those in urban areas use the Internet vs. 63% of those in rural ones (Pew Internet, 2008). For income the highest Internet use is 94% of households with incomes over \$75,000 vs. 77% of those with incomes of between \$30,000 and 49,999 and 57% of those with incomes below \$30,000 (Pew Internet, 2008).

People use the Internet for a range of purposes. Almost everyone, 91% of adults online, uses email, including 79% of those over 73 who are online (Pew Internet & American Life Project, 2009). The next most popular activities are using search engines (89%), researching products (81%), getting health information (75%), getting weather/news (70%), and making travel reservations (68%) (Pew Internet & American Life Project, 2009). Health information via the Internet is popular with all age groups and ranges from 67% of those 73 and older to 82% of those aged 33-44 (Pew Internet & American Life Project, 2009). A study done among 12,878

households found that those seeking information on the Internet were more likely to have serious health problems or be uninsured (Bundorf, Wagner, Singer, & Baker, 2006).

**Online cancer resources.** Cancer patients come to the Internet for: 1) communication, via email; 2) community, via online discussion boards or support groups; 3) content, via online health information; and 4) e-commerce (Eysenbach, 2003). “Studies have shown that the overwhelming majority of cancer patients tend to want as much information as possible about their illness” (Huang & Penson, 2008, p. 203). For information and education, Web sites like that of the National Institute of Health, the National Cancer Institute and the American Cancer Society provide basic information on the various cancers and their treatments. The National Cancer Institute, in addition to a phone hotline during the weekdays, also provides an online live chat option from 9 am to 11pm weekdays and will answer any email sent to them within 1-2 business days (National Cancer Institute, 2009). A review of information giving in those newly diagnosed with cancer concluded that having information can “increase patients’ control and involvement in their care, reduce their psychological distress, encourage better levels of adherence and instill realistic expectations” (McPherson, Higginson, & Hearn, 2001, p. 227). Participants to online cancer Web sites have become sophisticated users and are able to identify information of poor quality (Huang & Penson, 2008). Though there was initial concern about inaccuracies on the Internet, the recent interactive nature of online communities also allows for detection and correction of information (LaCoursiere, Knobf, & McCorkle, 2005). A study done among 41 users of online cancer sites concluded that there is an “untapped opportunity to improve the online information and support delivered to cancer patients” and to “correct misconceptions about cancer treatment” (LaCoursiere et al., 2005, p. 9)

Online cancer support groups have existed since the 1990s. A number of studies have explored why and how people participate in such groups and the benefits they receive from them.

Klemm did three descriptive studies analyzing content from postings on support group discussion boards (Klemm, Hurst, Dearholt, & Trone, 1999; Klemm, Reppert, & Visich, 1998; Klemm & Wheeler, 2005). These showed that information and support, either sought or given, accounted for almost 80% of posted messages. There were gender differences with women posting significantly more than men: 22% of women with breast cancer vs. 8% of men with prostate cancer (Klemm et al., 1999). Cancer caregivers also described the emotional challenges of caring for a loved one with cancer and their need for support from other caregivers (Klemm & Wheeler, 2005). Other descriptive studies have explored the self-help approach that online groups use offering encouragement, social support, and information (Klemm & Hardie, 2002; Sharf, 1997). The appeal of these Internet groups in regards to giving and receiving support and information is explained by the key attributes of online communication:

***Interactivity.*** This is a “defining feature of online technologies, with a particular focus on tailoring content to users, increasing engagement in decision making, improving learning, increasing attractiveness, and enhancing the influence of online services (Walther et al., 2005, p. 4).

***Presence.*** Online, physical presence is irrelevant and is instead replaced by social presence, which can be just as meaningful to cancer patients (Walther et al., 2005). People on online support groups are “there” for each other, even though they never meet in person.

***Homophily.*** This is shared common experience. Here the “social similarity of online communicators who have a common life experience...drives identification and relating in online interaction” (Walther et al., 2005, pp. 7-8). The benefit is being in touch with others who share the same physical and emotional issues (Walther et al., 2005).

***Social distance.*** An interesting aspect of online support groups is that even though cancer patients have things in common, they are also strangers to one another. Such connections are

considered “weak ties”, people with important expertise who are not close friends or relatives (Walther et al., 2005). Being strangers allows participants to manage stigma and embarrassment.

***Anonymity and privacy.*** Related to social distance is the fact that most people participating in online communities do not provide their full names or personal information. This encourages disclosure “without having this information connected to their offline lives” (Walther et al., 2005, p. 10). The one-on-one interaction with the computer gives participants a sense of privacy. This enables the disclosure of intimate details that strengthens connections and further builds the community (Walther et al., 2005).

***Interaction management.*** The final key attribute is that participants can choose whether, when and how much online interaction is comfortable for them. They can “avail themselves of system resources opportunistically” (Walther et al., 2005, p. 11). This allows individuals who are ill to avoid struggling with the reciprocity implicit in offline interactions. Online messages can also be edited to insure they communicate exactly what the participant wants. This “facilitates the purposeful and deliberate choice of words users employ when they describe difficult issues or work to provide sensitive responses” (Walther et al., 2005, p. 12).

**Online pancreatic cancer studies.** There are only two studies about pancreatic cancer and the Internet. Both have to do with aspects of the JHPCRC discussion board. The first analyzed 300 consecutive chat room posts before and 300 after a frequently asked question (FAQ) module was added to the Web site (Coleman et al., 2005). A descriptive-comparative mixed methods design was used. The three major themes identified from the postings were information, support, and reporting. Information and support were further broken down into the subcategories of seeking, giving, and both. These subcategories confirmed previous data that online cancer support group participants *give* information and support in addition to receiving it (Klemm et al., 2003; Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2003). The largest theme

identified was information, which accounted for 50% (n=230) of the pre FAQ postings, and 61% (n=241) in the post period (Coleman et al., 2005). Within information, the seeking subcategory was the largest with 54% (n=123) in the pre period and 71% (n=170) in the post (Coleman et al., 2005). The second major theme, support, represented 31% (n=141) of entries in the pre FAQ period and 24% (n=96) in the post (Coleman et al., 2005). The third theme of reporting was the smallest of the three and consisted of people giving updates on their loved one's health status or death. The authors concluded that the addition of the FAQ increased the posts for information seeking by 17% (Coleman et al., 2005). They noted that this increase was "surprising" given the addition of the FAQ, but further analysis showed that "questions about medical treatment decreased whereas the number of questions about prognosis and end-of-life care, questions not included in the FAQ or on the Web site, nearly doubled" (Coleman et al., 2005, p. 467). Of the 72% of posters who could be identified, only 8% were patients (Coleman et al., 2005). The remainder were various family members and friends (Coleman et al., 2005). In the article's limitation section, the authors noted the convenience sample as a limit to generalizability and also speculated that the low level of patient involvement might not be representative. Not noted in the limitation section is that a bereavement discussion board had also been added to the site just before the FAQ, which could also have changed the nature of postings in the post period.

The second study of the JHPCRC discussion board analyzed the same 600 postings for spiritual themes (Nolan et al., 2006). It also used a descriptive-comparative mixed methods design. Four themes were identified: spiritual convergence, reframing suffering, hope, and acceptance of the power of God and eternal life (Nolan et al., 2006). The site also served a bereavement function as 6% of the postings were by family members reporting on the death of their loved ones (Nolan et al., 2006). The study's conclusion was that spirituality is an aspect that developing cancer Web sites should consider addressing (Nolan et al., 2006).

### **Remote healthcare providers**

***Telemedicine.*** According to a review article from 2002, telemedicine is “the use of electronic information and communications technologies to provide and support healthcare when distance separates the participants” (Field & Grigsby, 2002). Interactive video telemedicine began in the 1960’s as part of providing neurologic and psychiatric services in rural Nebraska (Field & Grigsby, 2002). Growth in telemedicine was slow until 2001, when Medicare revised its coverage to include interactive audio and video services (Field & Grigsby, 2002). A Cochrane review in 2000 identified seven trials of telemedicine applications involving more than 800 participants (Currell, Urquhart, Wainwright, & Lewis, 2000). One involved telemedicine and an emergency department, one used video consultations between primary care providers and a hospital’s outpatient department, and the rest involved remote home care or patient monitoring. The review concluded that “although none of the studies showed any detrimental effects from the interventions, neither did they show unequivocal benefits and the findings did not constitute evidence of the safety of telemedicine” (Currell et al., 2000, p. 1).

A review of “telemental” health practices in 2008 analyzed 65 studies (Hailey, Roine, & Ohinmaa, 2008). Half the studies, 32, were of high or good quality. Evidence quality was higher for Internet and telephone-based interventions than for video ones. The most successful applications were for child psychiatry, depression, dementia, schizophrenia, suicide prevention, posttraumatic stress, panic disorders, substance abuse, eating disorders, and smoking prevention. Less convincing was evidence for general telemental programs and ones addressing obsessive-compulsive disorder. The review concluded that the evidence was limited, but encouraging (Hailey et al., 2008).

***Use of telemedicine in palliative care.*** There are several examples in the literature of hospice or palliative care being provided as a type of telemedicine, in most cases by phone. The

most significant one was a longitudinal RCT conducted among 322 patients with advanced cancer in a rural area (Bakitas et al., 2009). The study's goal was to determine the effect of an APN-led intervention on quality of life, symptom intensity, emotional state, and use of resources by patients with newly diagnosed advanced cancer (Bakitas et al., 2009). Patients were randomized to a control group that received usual care or the intervention group that received the ENABLE program. This was a multidimensional psychoeducational intervention consisting of four weekly sessions and monthly follow-ups until death or the completion of the study (Bakitas et al., 2009). It followed a chronic care model and used a case management and educational approach to encourage patient participation, self-management and empowerment. Quality of life was evaluated using the Functional Assessment of Chronic Illness Therapy for Palliative Care; symptoms were assessed using the Edmonton Symptom Assessment Scale; and mood was measured by the Center for Epidemiological Studies Depression Scale (Bakitas et al., 2009). Intensity of service was measured by the number of hospital days, days in the Intensive Care Unit (ICU), and the number of Emergency Department visits (Bakitas et al., 2009). Measurement was done at baseline, at one month, and then every three months until death or the end of the study. To improve access to patients in this rural area, a manualized telephone-based approach was used with two specially trained APNs conducting the four initial telephone educational sessions and then the monthly telephone follow-ups. Each of the four educational sessions had an assigned module covering problem solving, communication and social support, symptom management, or advance care planning (Bakitas et al., 2009). The telephone sessions lasted from 30 to 41 minutes and the APNs were also available by phone for any additional issues. Patients were referred by the APNs to their oncology or palliative care teams if new issues arose, or to ancillary resources as needed. In addition, participants and their caregivers were invited to attend monthly group shared medical appointments in person, led by a certified palliative care physician

and nurse practitioner. The results showed that patients in the intervention group had higher scores for quality of life and mood over the study period, but did not have improvements in symptom intensity scores or reduced resource use/hospital days. Relevant to the capstone project, 41% of patients had some type of advanced gastrointestinal (GI) cancer, although the article does not specify the types of GI cancer. Also, the article notes that this is the first RCT that tested a palliative care intervention concurrent with oncology treatment, as is recommended by the field and shown on Figure 1 of this report.

Another study described a more modest telephone service (Palcall) for rural home palliative care patients (Campbell, Harper, & Elliker, 2005). Patients could register to have access to an experienced palliative care registered nurse on duty at the sponsoring in-patient hospice. This nurse had access to medical information for subscribed patients. Half the calls to the in-patient nurse were for symptom control and the other half for support. Many of the calls, 44%, came on the weekend or holidays when the patients' primary care providers' offices were closed. The palliative care nurse was able to address the issues in 71% of cases. For the others, the Palcall nurse referred the patient case to an on-call physician or visiting home nurse who went out to see the patient. Callers were predominantly caregivers (64%) with only 22% of calls being from patients. No outcome measures were reported, but the effort was deemed financially and clinically successful (Campbell et al., 2005).

A similar service is described by Roberts, Tayler, MacCormack, and Barwich (2007) in which an existing nursing tele-triage and health information phone service was enhanced to include palliative care information. Dying patients and their caregivers could call this service after hours for direction on managing symptoms and other end-of-life issues. The outcomes were improved symptom management, decreased emergency room visits, and improved support for caregivers (Roberts, Tayler, MacCormack, & Barwich, 2007).

***Palliative care -related remote providers.*** A number of studies of online providers deal with aspects or areas related to palliative care. These include 1) grief; 2) pain management; 3) depression; 4) anxiety; 5) emotional distress; and 6) issues specific to cancer patients. The most pertinent are summarized on Appendix C. These studies range from two qualitative studies to three RCTs. Their evidence evaluations range from I B (a high level of evidence with moderate quality) to III B (the lowest level of evidence with moderate quality) using the Johns Hopkins Evidence Appraisal (Newhouse, Dearholt, Poe, Pugh, & White, 2007). However, the study of online interventions is an emerging area, and so protocols and study instruments are relatively new and need further validation. Nonetheless, most studies showed a benefit to the use of online interventions by experts. The most pertinent studies are summarized below.

***Complicated Grief.*** Wagner has studied the use of online providers to treat or prevent complicated grief (Wagner et al., 2006; Wagner & Maercker, 2007, 2008). The latest study was a pilot done among 35 bereaved individuals at risk for complicated grief (Wagner & Maercker, 2008). The three-week intervention consisted of writing assignments on the circumstances of the loved one's death, cognitive restructuring, coping with bereavement, their bond with the deceased, and social sharing with family. A professional therapist reviewed the assignments and provided feedback. Communication was asynchronous and only done via email. Completer and intent-to-treat analysis suggest that this intervention led to a significant reduction in complicated grief symptoms and depression. This was a similar intervention to one tested previously that had reduced complicated grief symptoms in a similar population and then maintained that reduction over 14 months (Wagner et al., 2006; Wagner & Maercker, 2007). These studies are relevant to the capstone project in that the study populations are similar given the high mortality/short survival of people with pancreatic cancer and that their loved ones may be also at risk for complicated grief. The medium for interaction with the PCNP is also online writing.

*Pain Management.* A large sample, longitudinal RCT published in 2002 explored whether the Internet could be used to improve health status/reduce pain and reduce healthcare utilization for people with chronic back pain (Lorig et al., 2002). It used a discussion group and professional providers interacting with participants. Inclusion criteria were having been seen and diagnosed at least once in the past year for back pain without signs of neurological complications or significant dysfunction. The intervention had three parts: a professionally moderated listserv email system where all participants received each other's emails, a copy of a previously tested handbook about back pain, and a videotape with tips for maintaining an active life with back pain. The listserv/discussion group had two moderators and three content experts: a physician, a physical therapist and a psychologist. There were no specified discussion topics and the online experts served as resources for answering general questions and moderating any discussion. Participants were randomized to either the intervention or the control group, which received usual care and a subscription to a popular non-health related magazine. During the yearlong study period, 2399 emails were posted to the intervention group (Lorig et al., 2002). At the end of the year, treatment subjects showed significant improvement on pain, disability, role function, health distress, and health care utilization vs. the control group. In terms of relevance to the capstone study, it is difficult to isolate the impact of the email component of the intervention. However, the on-going interest in the emails suggests participants found the moderated discussion board valuable.

*Anxiety.* A meta-analysis of 19 RCTs published in 2009 focused on Internet and computer-based cognitive behavioral therapy (CBT) for anxiety. The weighted mean effect sizes showed that Internet-based CBT was effective and superior to the control group's outcome measures. Eleven of the 19 studies included regular contact with an online therapist. These therapists provided coaching, feedback, or on-going communication via email to participants.

Total time with the therapist, when noted, ranged from 76 to 360 minutes (Reger & Gahm, 2009). The sample sizes for the studies were not large, 25-186 (Reger & Gahm, 2009). Because of the varying study interventions and details, the only conclusion relevant to the capstone project is that online interaction with a trained provider can address and improve issues like depression, anxiety, general distress, dysfunctional thinking, and quality of life.

***Online facilitators for cancer.*** Gustafson et al. (2001) completed an RCT of the impact of a computer-based support system (CHESS) on the quality of life of younger women with breast cancer. The study involved giving in-home computers to 246 women below the age of 60 who had been newly diagnosed with breast cancer. The control group received the standard intervention, which was a copy of Dr. Susan Love's Breast book. The intervention group got the in-home computer with CHESS.

CHESS was a comprehensive support program with three components. The first was information, developed by clinicians and patient panels. The second component was support services in the forms of an online, moderated discussion board, an Ask an Expert link, and a personal stories section with narratives on coping from others with breast cancer. Finally, the third component was a decision services/coping advice section. Professional providers were involved in the moderated discussion board, the Ask an Expert link, and the coping advice components. After a five-month period, the intervention group had higher levels of social support as measured by a social support tool developed by the CHESS team. They also showed greater confidence about their computer skills than did the control group. However, as this study involved multiple elements, it is difficult to analyze the specific effect of the online provider.

### **Economic Considerations**

There is not yet a viable business model for an online-only health service. This is often the case for new healthcare ventures. "Pioneer healthcare programs are difficult to finance

because traditional reimbursement streams typically will not pay for their services until these new programs become almost old programs that have proliferated and proven their effectiveness time and again” (Brumley, 2003, p. NA). In fact, the Internet business models that currently exist tend towards services being provided for “free” (Anderson, 2009).

Although patients and families may appreciate interacting with an online PCNP, it is not known whether they would pay for such an interaction, particularly when they can access other patients and families on the existing discussion board. If insurers or other medical payer systems agree to pay for such a service, a system would need to be developed to confirm that the service had been delivered/received. This would require changes to reimbursement and billing practices. Government entities such as CMS would need to be involved in such a change as would major insurers and other healthcare stakeholders. In the short term, it is most likely that online health services, such as the PCNP Web page, will need to be provided free to participants and paid for by their sponsoring health systems as a way to 1) improve public relations; 2) increase patient referrals; or 3) reduce the demands for information/emotional support on other clinical staff.

### **Systems Analysis**

Using concepts from complex adaptive systems (Porter-O'Grady & Malloch, 2007), the PCNP Web page innovation is a local change occurring directly between participants and the PCNP. It is also part of the broader systems of pancreatic cancer care, end-of-life care, the Internet and eHealth. It is itself very simple, but contributes to these complex systems. By providing patients and their families with informational and emotional support, the PCNP Web page will ideally add value to these broader systems. Along with other palliative care and online health efforts, this innovation may ultimately change pancreatic cancer or end-of-life care from the center/point of service outward.

However, such change is not without challenges. The constant tension between equilibrium and disequilibrium means a system is always trying to find balance. Right now, it is out of balance with patients with pancreatic cancer, and their families, needing more types of support and holistic care than has been traditionally provided. Palliative care strives to address that imbalance but, by being a discontinuity, also contributes to disequilibrium. Once new innovations, such as the PCNP Web page, become established, the system reaches a new state of equilibrium until another challenge or opportunity comes along.

Providing palliative care, or any type of healthcare, online will challenge the status quo in several areas. First, standards of care will need to be revised to include online health interactions. Then certification and licensure may need to be changed to acknowledge the potentially national or international interactions. Currently, U.S. health care providers are licensed by state and certified nationally. The PCNP for this project is licensed to practice in Maryland. Potential online practice, however, could extend beyond the provider's local/ national location. An area of concern is that of confidentiality. Could patients be assured that they are providing personal health information via secured networks and, conversely could providers be assured that their responses were indeed being kept private. Billing and reimbursement would have to change to support non-personal/physical interactions between online providers and patients. Quality assurance and safety measures would need to address the unique issues of online interaction and practice. Cultural and geographical differences would have to be addressed so that patients in one health system might be able to appropriately interact with providers in another. Finally, ethics would need to be considered to insure that the integrity of the healthcare interaction would be maintained for all involved.

These challenges will result in trial and error approaches. Errors along the way will contribute to learning and to the creation of a new, more online healthcare system. The Internet

also provides an opportunity for diversity and innovation since the cost of entry is minimal. This allows any provider to potentially establish an online practice. Hopefully, the new online components will function well and interact and intersect with the existing healthcare system. This could add vitality to that system as more patients' and families' needs are better addressed in ways that are new and interactive.

## Section Three

### Methodology

**Project design.** This project used a mixed method design including qualitative and quantitative descriptive methods (Sandelowski, 2000). A quantitative approach was used to assess the volume of participation with the PCNP Web page. A qualitative approach was used to determine the palliative care needs of those posting to the PCNP. A mixed method approach can “expand the scope and deepen (the) insights from studies” (Sandelowski, 2000, p. 246). This is because “different aspects of reality lend themselves to different methods of inquiry” (Sandelowski, 2000, p. 247).

**Quantitative approach.** A descriptive quantitative design was used to provide information about the volume of participation with the PCNP Web page. The quantitative data was collected from the number of visits to the Web page, the number of posted questions and emails people sent to the PCNP, and answers to the online survey (Appendix D) evaluating the experience with the PCNP Web page.

**Qualitative approach.** A qualitative approach was used to determine the palliative care issues identified by patients and families posting to the PCNP. The content from the questions and email interactions with the PCNP was analyzed and clustered within the eight domains from the National Consensus Project. The priority issue was identified for each posted question and email. Additional issues were noted as secondary ones. Inductive analysis was used to determine the palliative care issues raised, to categorize the PCNP responses to the palliative care issues in the postings, and to summarize responses to the online survey’s open-ended questions.

### Setting

**Johns Hopkins Pancreatic Cancer Research Center (JHPCRC) Web site.** A PCNP Web page was placed on the JHPCRC Web site (see Appendix E for the Web site’s homepage).

The JHPCRC Web site was developed in 1995 by resources within the Johns Hopkins Pathology Department to provide information to patients about pancreatic cancer and its treatment. The unmonitored discussion board was an early feature and is archived on the site back to November of 1996. The Web site offers resources grouped into the following four key areas: 1) patients/families; 2) healthcare providers; 3) advocates and donors; and 4) a section on the JHPCRC multidisciplinary clinic. In addition, there is a physician “blog” and a section on the discussion board where people can post memorials of loved ones called the “patient/caregiver bio board”.

The Patient and Family Web page (Appendix F) outlines the various Johns Hopkins services and resources. These are divided into three sections. The first is entitled “Johns Hopkins & You” and under it are links to information on “Choosing Johns Hopkins”, “Evaluating my case”, “Becoming a Hopkins patient”, the “Pancreas multidisciplinary clinic”, “Participating in research”, and “Raising awareness.” These provide ways to make an appointment to be seen and evaluated at Johns Hopkins. Many of the patients seen at the Multidisciplinary clinic come because of the Web site (Coleman, 2009). The second major section is “Patient education” with links to pages on “Basics of pancreatic cancer”, “Diagnosis”, “Treatment”, “Intraductal papillary mucinous neoplasms”, “Islet cell tumors & endocrine neoplasms of the pancreas”, “Research presentations”, a bibliography, and “Other pancreas sites”. Under “Treatment” there are ten sections, which cover a range of treatment options from surgery to nutrition information and pain management. Finally, there is a “Support services and research” section. Clicking on “support” brings you to a page where there is information on “Genetic Testing Related to Pancreas Cancer”. Below that is a section called “What should we expect during the final stages”. Under that heading is a link to HospiceNet, a Web site that provides information to patients and families about what hospice is, what services it offers and how to access them.

**PCNP Web page.** When the study period began on Monday, November 9, 2009, a new Web page for the PCNP was added to the JHPCRC Web site (Appendix G). The title of the page was “Ask a nurse practitioner about symptoms, problems, and concerns”. This terminology was chosen as a way to describe what the PCNP would do rather than using “palliative care” since many people are unfamiliar with that term. The PCNP Web page featured the details of the study and a description of palliative care in layman’s terms. There was also information about the PCNP including her photo, professional training, and credentials. There were links to the PCNP Web page from the JHPCRC discussion board, treatment and care, and support sections.

On the PCNP Web page there was a “comments” section for people to write or “post” questions to the PCNP. The PCNP Web page was set up like a blog in that any postings were first made available only to the PCNP for approval. This was done to prevent anyone from posting inappropriate or inaccurate information on the public site. The PCNP approved all messages without making any changes and these were then displayed to anyone coming to that page. The PCNP responded within 24 hours of each posted question (or on Monday if the question was posted over the weekend) and that interaction was also visible to anyone viewing the Web page (see Appendix H for a sample of the questions and responses).

In addition to the public comments area, there was an opportunity for people to email the PCNP directly with questions. Finally, a link from the PCNP Web page took people to an online survey. This survey allowed for anonymous evaluation of the PCNP Web page. Putting the link to the survey on the PCNP Web page was the most convenient way to make it easily available to anyone coming to that page. Anyone sending the PCNP an email saw the link on the PCNP page first, but was also encouraged to complete the online survey in the PCNP’s email response.

**Sample.** The sample was a convenience one of those accessing the PCNP Web page. This sampling method was the most practical way to identify participants who might be

interested in the PCNP resource. There were three sub-samples studied. The first sub-sample was the number of visits to the PCNP Web page. Due to the online nature of the project, it was not possible to confirm how many unique individuals visited the PCNP Web page. The Web site did not require a login, so there was no way to confirm how many visits might be coming from the same person. While tracking technology could tell which specific computer a visitor came from, people use multiple computers and so the same person may have visited from a computer at work and then again from one at home.

The second sub-sample was that of the questions and emails posted by patients and families of those with pancreatic cancer. A subset of those visiting the Web page posted questions or emails to it. Those who do not post are called “lurkers” and often derive benefit from online situations like discussion boards, but are not necessarily comfortable posting to them (Idriss, Kvedar, & Watson, 2009). In this second sub-sample, it was possible to determine whether the same person posted multiple questions or first posted a comment and then sent the PCNP an email. This was because posters were able to fill in a name with their question. As with the visits sub-sample, each of the questions was considered a separate “participant.” The emails had an address, so it was possible to see if they were from different individuals. Again, each individual email was considered a unique “participant”. Because of the interactive nature of the PCNP page and emails, some participants posted a follow up question or email to the PCNP’s response. Responses and results were sometimes combined for the same poster/emailer.

Finally, the third sub-sample were those who completed the online surveys. This survey was available to anyone coming to the PCNP Web page.

***Inclusion and exclusion criteria.*** The inclusion criteria for the samples was that all visits, questions/emails, and surveys were considered “participants”, even if the questions/emails

and survey responses did not address palliative care issues. Those below the age of 18 were discouraged from participating to insure that minors were not involved in the study.

### **Key Definitions, Variables, and Instruments**

**Definitions.** The following are the key definitions for this project. Appendix I provides a list of all the definitions for the Internet-related terms used in this project.

*E-Mail (electronic mail).* This is defined as a service that allows people to send messages with text, files, etc. from their computer to any other computer in the world. These messages could only be read by the individual(s) who has access to the email account.

*Family.* This is defined as anyone other than a person with pancreatic cancer. It may include relatives, friends, other loved ones, neighbors, colleagues, etc. Anyone posting a comment or email regarding someone else with pancreatic cancer was considered “family”.

*Participant.* This is defined as anyone who came to the PCNP Web page.

*Posting.* This is defined as text written or “posted” in the comments section of the PCNP Web page. These were real-time communications over the Internet. Emails to the PCNP were also considered postings.

*Poster.* This is defined as anyone who posted a question to the public comments section of the PCNP Web page or sent the PCNP an email.

*Survey respondent.* This is defined as anyone who filled out the online survey.

*Web page.* This is defined as a page or file on a “Web site”. Each Web page has an “address” that is based on the Web site’s URL. The address for the PCNP Web page was

[https://apps.pathology.jhu.edu/care/?page\\_id=2](https://apps.pathology.jhu.edu/care/?page_id=2).

*Web site.* This is defined as a collection of files or “Web pages” linked together and available on the World Wide Web. Each Web site has its own “address” (URL). The URL for the JHPCRC Web site is <http://pathology.jhu.edu/pancreas/>.

***Variables and measures.*** Several variables were measured. First, the visits, or traffic, to the PCNP Web page were tallied. A tracking system, Google Analytics, identified how many participants “visited” the page, how long on average participants stayed on that page, how they came to the page and their location by country based on the participant’s computer’s IP or Internet protocol address. This gave an indicator of how many “people” found their way to this Web page. Some of the visits were brief (i.e. if people navigated to the PCNP Web page by accident or quickly decided it was not of interest). Therefore, traffic to the Web page alone was an imprecise measure of interest. For that reason, in addition to the traffic, the number of questions and emails to the PCNP was tracked. These also formed the basis of the data to be analyzed for the palliative care needs assessment. Evaluation outcomes were the respondents’ responses to the online survey.

***Quantitative instrument.*** The online evaluation survey was the only instrument (see Appendix D). This survey used Survey Monkey software and had questions to determine the level of the respondent’s participation with the PCNP Web page. The survey asked for demographic information on age, race, level of education, gender, and whether the respondent was someone with pancreatic cancer or a family member. There were two questions about the helpfulness of the PCNP, using a five-point Likert scale ranging from 1) not helpful, to 5) very helpful. There were also six questions about the different types of support the PCNP might have provided. These support questions were taken from the information and emotional subscale of the Medical Outcomes Study (MOS) Social Support Survey (Sherbourne & Stewart, 1991). This survey was developed and validated in 1991 as a comprehensive way to assess the various aspects of social support for patients with chronic conditions (Sherbourne & Stewart, 1991). In its original form, it consisted of 19 questions in a five-point Likert scale format across four subscales (Sherbourne & Stewart, 1991). It has been used in several subsequent studies and

validated in various other and shorter forms (Gjesfjeld, Greeno, & Kim, 2008; Nandi, Tracy, Aiello, Des Jarlais, & Galea, 2008; Zatzick et al., 2002). It has not been used in research involving palliative care nursing and was modified in this project to only include the questions from the informational and emotional support subscale. Finally, there were open-ended questions about what participants liked the most/least about the PCNP Web page and any suggestions as to how to improve the page.

**Qualitative.** Qualitative data were collected from participant responses obtained from the Web page postings and online email interactions with the PCNP. The issues raised in the questions/emails were initiated by the participants and, therefore, not guided by the PCNP. The sets of data that were analyzed included the issues raised by patients and family members, the primary and secondary issue(s) identified in each posting, the responses given by the PCNP, and the responses to the online survey's open-ended questions.

**Procedures.** Prior to the beginning of the study, human subjects (institutional review board) approval was obtained from the Web site's provider, the Johns Hopkins University, and the researcher's academic institution, the University of Maryland Baltimore. Administrative approval was also obtained from the director of the JHPCRC, Dr. R. Hruban, and the Web site's administrator, Mr. J. Doran.

**Screening, enrollment, consent.** The only exclusion criteria for this study was participants below age 18. This was not possible to enforce, given the online nature of the study, but in reading posted questions and the online survey responses, it seems unlikely that any came from someone under age 18.

In regard to enrollment, at the beginning of the study period announcements of the availability of the PCNP Web page were placed on the JHPCRC Web site's home page, discussion board, support, and news areas (Appendix J). These announcements had a link to

easy-to-understand information on what palliative care was, why it was relevant to this patient population, and the types of issues it addressed. The role and credentials of the PCNP were also explained. It was made very clear that this was a research study, that the PCNP would be available for a limited period of time, and that feedback on this resource/experience was being sought. These announcements remained on the JHPCRC Web site throughout the study. Notices on the PCNP Web page encouraged participants to click on the link to the online survey. People interacting with the PCNP via private emails were also encouraged to fill out the survey. Filling out the survey implied consent since the survey made it clear that the participation in the study was voluntary and that people did not need to fill out a survey in order to interact with the PCNP. Specifically, the instructions on the survey were “By filling out this survey you are agreeing to participate in the study. Your participation in the study is voluntary. You will not be asked for any information that will identify you. There may or may not be a benefit to you in participating in the study. The study is not likely to cause any potential risks.”

**Data quality control and management.** Reliability was confirmed by the use of the same instrument among the same population by the same researcher over a limited period of time (Burns & Grove, 1995). The data was under the exclusive control of the researcher and the JHPCRC’s Web site administrator throughout the study. Data from the questions/emails was recorded “as is”, with no editing for spelling or grammatical errors. Numerical data was recorded in an Excel database and was “cleaned” at the end of the data collection period to insure that it had been input properly. All participant information from the postings was non-identifiable, or de-identified, before entering into the database. Email addresses from the private emails were secured by the PCNP on a password-protected computer. The survey data was secured in an online Survey Monkey account, which was only accessible via a login and password.

### **Data Analysis**

**Quantitative analysis.** The data from the Web page's traffic, the number of questions/emails and the demographic and Likert scale scores from the online survey were analyzed with descriptive statistics. Specifically, the absolute and relative frequencies were analyzed. The Survey Monkey software provides this information along with ways to filter the data using different respondent parameters. Independent t-tests and Mann-Whitney U tests were done among the Likert scale scores to test for statistical significance. Once in categories, the data for the palliative care domains were quantitative at the nominal level and also were summarized with descriptive statistics.

**Qualitative analysis.** Microsoft Word software was used to assist in categorizing the postings and responses. The downloaded questions and emails from the PCNP Web page were copied to appropriate Word files. The qualitative analysis first identified the problems/issues raised in the postings. Each of the problems/issues identified was then assigned to at least one of the eight palliative care domains. A question about pain management was categorized as domain #2, physical aspects of care. A question whether a loved one was close to death was assigned to domain #7, care of the imminently dying patient. Some postings raised issues that fit into several of the palliative care domains, thus the initial analysis may have been assigned to more than one domain, e.g. one that addressed pain and emotional concerns. Other issues that did not fit properly into any of the specific domains were coded as "other." In addition to the domains, sub-themes were identified for some problems/issues. For instance, issues in the physical domain were further categorized by the type of symptom i.e. nausea, pain, anorexia. The second analysis involved selecting the priority issue raised in each posting. After the postings were analyzed, it was decided to also inductively analyze the PCNP's responses to the postings.

The researcher and an expert qualitative researcher, Dr. Wiegand, performed the inductive analyses independently. They then met and reviewed the data. Consensus was achieved

readily for most of the data. In some cases it was difficult to determine which domain the posting best fit. The researcher and Dr. Wiegand discussed these situations and then jointly agreed on the domain assignment(s). The open-ended survey responses were also analyzed and placed into appropriate categories by the researcher and then confirmed with Dr. Wiegand.

## Section Four

### Results

#### Traffic to the PCNP Web page

*Visits/visitors.* The Google Analytics report for the PCNP Web page showed a total of 707 visits from November 9, 2009 to January 3, 2010. This traffic was fairly even across the study period at 5-10 visits per day with a peak of 25 on November 16<sup>th</sup>. Included in the total visits, however, are some by the researcher as the analytics system is not able to factor those out of the data. This could account for at least 60 of the total visits. Therefore the correct total is closer to 650 visits. The inclusion of the researcher must be kept in mind when looking at all traffic data.

Roughly half of the visits, 51.5%, were from people new to the page. In terms of individual visitors/computers, there were 398 unique IP addresses/visitors across the study period of which only 3 were the researcher. (Some additional ones may have been associates of the researcher who went online to see the Web page during the study period.) For perspective, this compares to 14,431 total visits to the JHPCRC Web site for the same period of which 10,982 were unique. The traffic to the PCNP page was 3-6% that of the total JHPCRC site.

*Source of visits.* Most visits, 87% (n=617) were referred from other pages of the JHPCRC Web site. Almost half of the visits, 49% (n=344), came from the JHPCRC discussion board. Some visits, 11% (n=80), came from participants directly typing in the PCNP Web page address. These were likely repeat visitors who may have bookmarked the page. Finally, 1% (n=10) came from search engines like Google and Yahoo via various combinations of the key words “johns hopkins”, “pancreatic”, “diagnosing”, and “blog”. Geographically, visitors came from 28 countries with the US representing 90%

(n=633) of the visits, the UK and Canada each representing 3% (n=20) visits, and other countries having only 1-4 visitors.

***Time on the page.*** Visitors spent an average of 4 minutes and 4 seconds on the PCNP pages during the study period. This compared with 1 minute 20 seconds for the overall JHPCRC site. The number of visitors who left the PCNP page immediately upon entering it, the “bounce rate”, was 34.8%. The JHPCRC site’s bounce rate for the same period was 51.4%. Again, however, when looking at the bounce rate and time on the page one has to factor in the researcher’s participation.

### **Online Survey Results**

**Demographics.** Only twenty people filled out the online survey during the study period. Most, 90% (n=18), were female. In addition, 95% (n=19) were white and 70% (n=14) were highly educated. In terms of age, 60% (n=12) were in the 50-69 age group and 80% (n=16) were spouses (1 husband, 6 wives) or children (1 son, 8 daughters). Only 15% (n=3) were patients. All patients were female, white, and none had posted to the PCNP. People posting to the PNCP represented 25% (n=15) of survey respondents. They were all female and mostly daughters.

**PCNP Web page feedback.** Most, 75% (n=15), of those filling out the online survey had only visited the PCNP Web page once. Of those who were repeat visitors, 60% (n=3) had come 2-5 times and 40% (n=2) 5-10 times. No one had come more often than 10 times. All twenty survey respondents felt that the PCNP should be an on-going resource on the JHPCRC Web site and that, if so, they would come to such a page a few times (75%, n=15) or even daily (25%, n=5). None chose the option of coming only “once or twice”.

**MOS social support tool.** The scores on the MOS social support tool were consistently high, particularly among those who had posted to the PCNP. The scores among posters ranged from 4.5 to 5.0 on the Likert scale with one being “none of the time” and five being “all of the time”. Statistical analysis in the form of independent t-tests and Mann-Whitney U tests were performed but found no statistical significance. The top-scoring question was whether the PCNP was “someone whose advice you really want”. This received an overall score of 4.55 and ranged from 4.38 among those who did not post to the PCNP to 5.00 among those who did. The other high-scoring question was “someone to give you information to help you understand a situation”. This received an overall 4.50 with a range from 4.27 among non-posters to 5.00 for posters. The lowest-scoring question was “someone to share your more private worries and fears with”. This got an overall 3.30, with non-posters averaging 3.0 and posters 4.5. Additionally, 38% (n=6) selected “doesn’t apply” for this question. Other questions with high numbers of “doesn’t apply” were “someone you can count on to listen to when you need to talk”, 39% (n=5), and “someone to give you advice about a crisis”, 36% (n=5).

The range in MOS scores for patients was 3.0 to 5.0. Adult children tended to rate the PCNP more highly than patients or spouses, but there were no differences in scores among different age or education categories (see Table 1).

**PCNP helpfulness.** The survey also asked “how helpful was reading other people’s posted questions and questions on the PCNP Web page”? Using a Likert scale with one being “not helpful” to five, “very helpful,” the overall score was 4.13. Again, posters rated the helpfulness higher, at 4.40, vs. non-posters at 4.00. Asked, “how helpful was any communication you personally had with the PCNP”, posters scored a 5.0.

**Like most/least about PCNP page.** Only half the respondents answered the open-ended question about what they liked the most about the PCNP Web page. Answers included having access to a knowledgeable resource, learning new information, and that the page was easy to use or ask a question. One daughter who posted a question to the PCNP said she liked best *“having a highly qualified knowledgeable person from Johns Hopkins available to address concerns, questions, and to offer advice written in layman’s terms that can be trusted and appreciated. It is wonderful that the tone of the answers is one of encouragement and hope”*. Another daughter who did not post a question said *“she is always available, compassionate, educationally sound, and answered questions that I have had regarding my father. Thank you for providing this service and choosing such a wonderful person to answer questions. I think this particular nurse practitioner is especially helpful”*.

In terms of what they liked the least about the PCNP page, there were only three responses. One was that there were not enough questions and answers; this person filled out the survey on December 10<sup>th</sup>, halfway through the project. Another made the point that the posts were not classified and so it was hard to scan them without key words. At this suggestion, the researcher added in key words to all posts so that people coming to the page could better review the topics. The third said that the PCNP *“didn’t have the answer I wanted”*. This came from a wife who had posted a question and, from the date of her survey, is likely one of the wives who asked about weight loss and was told that this problem was unlikely to be overcome. The only suggestion on how to improve the PCNP page was a comment that there was a technical problem with how to answer the Likert scale questions. This suggestion was made on November 19<sup>th</sup> and the online survey was corrected accordingly.

## Questions/emails to the PCNP

**Question/email results.** A total of 50 questions were posted to the PCNP Web page over the study period. An additional six emails were sent to the PCNP for a total of 56 postings. The analysis below is for the combined postings. A significant number of postings, 38% (n=21), were submitted within the first week of the project. The peak was at the end of the first week, on November 16<sup>th</sup>, when 9% (n=5) were posted, in line with the peak of traffic seen in the Google Analytics data for both the PCNP page and the JHPCRC site. After that peak, questions or emails were posted every few days, averaging 2-5 per week. Fewer were posted on weekends and on the days around the holidays of Thanksgiving, Christmas, and New Year. This was also in line with traffic to the JHPCRC Web page.

Some of the postings involved follow-ups/duplicates from the same people. Of the people posting to the public comments, 12% (n=6) posted a second or follow-up question. Of those who sent emails, 33% (n=2) sent a follow up email. One person posted a question and sent an email with the exact same question at the same time. That posting was counted only once in the analysis. Another individual posted two questions with very similar content within minutes of each another, which were answered jointly. Because they varied slightly, those postings were counted twice. Altogether 48 unique individuals posted or emailed 55 total questions to the PCNP. The PCNP provided 54 responses.

It was possible to determine some aspects of the identities of those posting, even though participants were able to post questions and emails anonymously. The participants were predominantly female (73%, n=35) although gender was not identifiable for 12% (n=6) of posters. In terms of identity, the largest group was daughters at 25% (n=12). The next largest group was wives at 19% (n=9). Only 6% (n=3) of respondents were patients,

although an additional 10% (n=5) of the posters had risk factors for pancreatic cancer. Of the postings, 85% (n=41) referred to a specific patient and it was also possible to determine some details about that patient. They were predominantly male, 58% (n=24), although gender was unavailable for 10% (n=4). Most were fathers and husbands, each 22% (n=9), then mothers, 15% (n=6), and various other family members or friends. The identities of 8% (n=3) were not discernable. From the descriptions given of these patients' situations, 27% (n=13) had end-stage pancreatic cancer and an additional 10% (n=5) were close to death.

There was no difference in the type of questions posted to the public PCNP page and those sent privately to the PCNP via email with the exception of one of the emails. That came from a nursing student who asked the researcher for input on a student project. Beyond that, the public questions often contained great detail while the emails were very short in a couple of cases. The identities of the other email authors also did not differ from the poster sample and were a husband, a male patient, and a daughter.

By the end of the project, there were 99 total posts for participants to read on the PCNP page: 55 questions and 54 responses. The text of this dialogue ran to ten Internet pages. Perhaps as a result, participants sometimes posted similar questions to ones that had been previously answered. These were responded to as if they had been posted for the first time. Each posting was analyzed to determine the primary issue or question being raised in it. Additional issues beyond the primary one were classified as secondary issues.

**Palliative care domains.** Among the 55 primary issues, 42% (n=23) were assigned to domain 2, physical aspects of care. The second largest category was domain 3, psychological and psychiatric aspects of care with 11% (n=6). Another 43% (n=24)

were assigned to the “other” category. As noted previously, some postings included additional issues that incorporated several domains. An additional 37 secondary issues were identified beyond the 55 primary ones. The largest category of secondary issues was psychological and psychiatric aspects of care with 27% (n=10). This was followed by 19% (n=7) in domain 1, structure and processes of care, and 19% (n=7) in domain 2, physical aspects of care. The “other” category represented another 19% (n=7) of the secondary issues. Details by domain are summarized below ranked by the volume of postings and full data for both the primary and secondary issues is shown on Table 2. Note, there were no postings for the domains of spiritual or cultural aspects of care.

***Domain 2: Physical aspects of care.*** This was the most frequent category of primary posted issues representing 42% (n=23). It was the second largest of the secondary issues with 19% (n=7). Questions in this domain focused on physical concerns such as symptoms from the illness or side effects from treatments. The most common issue was pain, followed by eating/nutrition and side effects from medication or pancreatic cancer treatment. An example of a pain issue was *“My husband had the whipple done in May... However since all treatments have stopped his so called “whipple pains” have intensified to the point where they occur several times a day and increase in intensity each time. The pains take his breath away and it’s hard for him to accomplish things, as you never know when they are going to strike. Is there any studies or treatment out there for these so called “whipple pains”?* (Quotes use the actual spelling and grammar of the postings.) An example of a nutrition issue was *“My mother has a stage IV Pancreatic Cancer. She has stopped eating and drinking and is extremely weak. However, she is completely conscious. We want to put her on nutritional IV but the hospice says that nutritional IV will turn into toxic in her body since she can't digest the food well due to her cancer. I would really appreciate it if you could tell us what you think”.* An example of a side effect issue was

*“My husband is on chemotherapy. He actually does well until about 3 days after when he develops "bone pain" I believe from the Neulasta injection. He is going back to work tomorrow and obviously would not be able to take any narcotics for the pain while working, what else would you suggest for this pain”?*

Some postings included multiple physical issues. One had the priority issue of weight loss but also included concerns about diarrhea, weakness, and frailty: *“My husband was dx'd w/ 2cm tumor in pancreas in January...Decided to do chemo only. PET in Sept. showed no visible tumor in pancreas or anywhere and CA 19-9 marker down to 24. Good news? Except for continued loss of weight and diarrhea. He was 192 in Nov. 08 and now at 148lbs. He eats well, no nausea but continues to lose weight. Dietician had lots of suggestions, we followed all, it is a little better but still no weight gain. Any suggestions? We are so concerned. He is 6'2" and thin as a rail, and very frail. He has been off chemo for 7 weeks now but still weak. Taking tincture of opium which has helped w/ diarrhea but what can he do to gain weight”?*

**Domain 3: Psychological and psychiatric aspects of care.** This was the second largest primary issues domain at 11% (n=6). Postings assigned to this domain dealt with the emotional issues related to pancreatic cancer. Only one posting asked about the psychological symptoms of the disease: *“My brother has been diagnosed with pancan and is having emotional mood swings. one minute he is crying, then he is mean, then sweet. he seems very tortured. is this a symptom of meds or an indication that it might have spread to the brain”?*

The most common theme in this domain was concern about risk: either of getting pancreatic cancer or what the implications were of symptoms for loved ones. An example of the first was: *“My dad died of pancreatic cancer aged 55 end of August after being diagnosed only 6 weeks before. I am 31 and I am worried that it is hereditary”?* This posting was one of four that expressed concern over a familial risk of pancreatic cancer. An example of concern over the

risk/implication of a symptom was this posting: *“I was dx'd with an IPMN Cyst in August 2009. I am planning on a Whipple in January 2010...I started recently testing my blood sugar and have noticed it runs over 100 usually around 130 and has been up to 150. In previous years when I would test it it was always under 100. Is this a new symptom that I should rush now into the Whipple or see an Endocrinologist”?*

**Domain 1: Structure and processes of Care.** This domain had only 2% (n=1) of the priority issues, but 19% (n=7) of the secondary ones. It included postings having to do with care processes. As palliative care is not yet widespread, the postings to this domain were mostly about issues the patients and family members were having with their current healthcare providers/system. The one posting that had this domain as a primary issue was from a wife who posted about struggles she was having with her insurance company over whether a PET scan was more appropriate than a CAT scan for her husband’s neuroendocrine/acinar cell diagnosis. Other issues in this domain ranged from concern about an inexperienced oncologist to how to get a second opinion to whether hospice was providing appropriate care.

**Domain 4: Social aspects of care.** The postings to this domain had to do with issues between the patient and family. None of the primary issues in the postings was in this domain, but 8% (n=3) of the secondary postings had it as an additional issue, such as *“Do you know if there are any signs to watch for? My mom doesn’t share too much unless I ask”*.

**Domain 7: Care of the imminently dying patient.** Although it was clear from the details provided in five of the posts that the patient involved was actively dying, only one posting’s primary issue was in this domain. Even in this example, the poster seems unsure of her father’s prognosis: *“MY DAD WAS DIGNOSE WITH PANCREAS CANCER NOV 24TH 09 HE CANT BREATH BACK HURTS.HOSPICE IS GIVING HIM 5MG 15MG 30 MG .HES CONSPATRD.AND HE CANT EAT.I CALL HOSPICE AND THEY ACT LIKE THEY AINT TO*

*CONCERN.IT SPREADED IN LIVER STOMCH SPLEENLUNGS.HOW CAN I HELP HIM.THEY GAVE HIM TWO MONTHS IM SCARED.ALL THIS MEDS ARE MAKING HIM NOT AWARE CAN YOU HELP ME*". This posting was also an example of one that covered multiple domains: physical, emotional, and processes of care.

Only 5% (n=3) of the postings mentioned hospice. This was often done with a sense of reluctance, such as "*Oncologist goal-get him through the holidays...not something we want to hear. Hopes to come home on hospice/home health care ASAP*".

**Domain 8: Ethical and legal aspects of care.** The postings assigned to this domain were not about making difficult decisions, such as treatment choices or life support, but problems with providers not providing appropriate care. Only 8% (n=3) of secondary issues were in this domain. An example: "*My BIL dx November 2007... Just started GTX last week. Xeloda began last Tuesday, and Gemzar and Taxodere injected on Friday. Saturday, he had to lay down in parking lot as he felt he couldn't breathe all of a sudden. He explains it as his throat is swelling, and someone is sitting on his chest. He layed in the car for an hour before it went away. Refused to go to ER. Later that night (about 12 hours later), it happened again. Same thing...an hour passed. A call to the Dr. was not encouraging at all! He recommended ROLAIDS.! This is his oncologist! Well, it happened for the 3rd time last night, and now waiting for the Dr to return his call*". This was the only posting in the project that required immediate response, as it was a potentially life-threatening medical situation.

**Other/ pancreatic cancer-related issues.** As noted, this was the largest category of primary issues at 43% (n=24). It also represented 19% (n=7) of secondary ones. Examples of a posting in this category included "*My aunt was just told today that she has cancer on both sides of her liver and also in her pancreas. They want to do more tests to see where the cancer began. They cannot operate on the liver and she cannot take radiation. What other options might she*

*have if any”?? Another example was “On the chat board there is discussion about a treatment for PC with lung mets. The treatments online thus far has only been abbreviated as "OFF". Thus far no one seems to know what "OFF" stands for, let alone if this treatment is a chemo protocol or surgery. I know as a nurse you probably can't give advice on this medical treatment. But if you could just please tell me what the abbreviation "OFF" stands for, I'd be most appreciative”.* Three postings did not have to do with pancreatic cancer. One was about dietary complications after gall bladder surgery, another about bone cancer (although this could have been metastases to the bone from pancreatic cancer) and one about an unusual non-cancer finding.

**PCNP responses.** Of the 54 responses, 49 were to posted questions and five to emails. Early on, the researcher established the following pattern: each response would answer the primary issue/provide the requested information and do so in an educational manner. This was so that others reading the response might learn about the posted issue. Each response would also provide some type of emotional or personal support. Often this was expressed as concern, e.g. *“I’m sorry to hear about his nausea”* or wishing people well, *“please take care,”* or *“best of luck to both of you”*. Finally, and when appropriate, hospice and/or palliative care was suggested.

The largest category of PCNP responses involved factual or educational information. Of the 54 total PCNP responses, 83% (n=45) provided some type of information. This information had to do with symptoms in 33% (n=18) of responses; diagnostic factors in 15% (n=8), treatment and genetics in 11% (n=6) each. Referrals were made in 85% of the PCNP responses (n=46), with services and providers suggested in 52% of them (n=24). Some responses contained multiple referrals for a total of 78. For provider referrals, the majority were to the patient’s current medical team/provider, 27%

(n=21), with new providers/specialists suggested in 8% (n=6). Hospice was suggested in 17% (n=13). Due to the online nature of the dialogue, other Web sites/links were included whenever possible. Among the 28 Web site links provided, other pages on the JHPCRC accounted for 32% (n=9), the Pancreatic Cancer Action Network (PanCan) in 25% (n=7), and the National Institute of Health's (NIH) Cancer Web site 14% (n=4). Links to four public access journal articles and one online medication package insert were also provided.

Beyond providing information, 15 of the PCNP's responses provided confirmation or acknowledgement to the poster. An example was "*You are right that ascites is usually a sign that cancer is moving into the last stage*". In 33% of these cases (n=5), the response confirmed that the patient being referred to was at the end of life, such as "*It is hard to know about (the physician's) estimate without seeing your mother, but, given her poor appetite and weight loss, it does sound like her time could be very limited*". In another third (n=5), responses broke bad news by saying that the situation being described was serious or terminal such as "*Ascites is a sign of advanced pancreatic cancer and so her time may be now very limited. You may want to check with her doctor to see what her prognosis is as hospice may be appropriate*". The concept of the benefit of the described treatment vs. its accompanying burden was raised in 20% (n=3) responses. An example was "*It all depends on what the goal of the chemo is. At this point it's probably palliative rather than curative, so its purpose would likely be to buy him some time. Then the question is how does he want to spend that time? If he has to eat to stay healthy for the chemo and he'd rather not eat so much, then it may ultimately be counterproductive*". The concept of goals of care was raised in 13% (n=2) of the PCNP responses. Finally, 17% (n=9) of the total PCNP responses included the disclosure that

the PCNP either did not know the answer to the posted question or that it fell outside of her area of expertise.

**Discussion board comments about the PCNP Web page.** There were several postings on the JHPCRC discussion board about the PCNP during the test period. On November 9th, the same announcement notice that was on the JHPCRC home page was also posted to the discussion board. This was responded to later that day with two postings: *“thanks for the information!”* and *“thanks so much”*. On November 10<sup>th</sup>, one of the people who posted a question to the PCNP posted to the discussion board to say *“What a great option to have. She responded to my question in one day”*. Someone else reminded the discussion board that the PCNP was available on November 13<sup>th</sup> saying, *“I think someone else posted about a new JHU offering...but just in case, I'll post the info. again. Nurse Practitioner who will answer questions about PC (pancreatic cancer), and she seems quite good and very responsive”*. Twice more during the project, on December 3<sup>rd</sup> and 16<sup>th</sup>, people suggested that those posting questions to the discussion board consider posting them to the PCNP. It is not possible to know whether those making that suggestion had themselves posted a question to the PCNP or whether anyone who posted a question to the PCNP did so at the suggestion of the discussion board.

## **Discussion**

**Overall.** The feedback to the PCNP from the postings, survey and discussion board confirms the previous evidence that people with cancer or their families come to the Internet looking for information and that it is possible to provide aspects of informational and emotional support there (Coleman et al., 2005; Eysenbach, 2003; Klemm et al., 2003; McPherson et al., 2001; Walther et al., 2005). Although no participant outcomes were measured, the feedback suggests the PCNP Web page was helpful and appreciated. The page was considered easy to navigate and use and participants found information and support there. The PCNP was clearly

seen as an expert whose advice was wanted, both to give information and also help the participant understand their situation. This was a validation of the use of an APN in this setting, as the PCNP had the training and experience to address the sometimes complex medical issues being presented while providing expert communication, a holistic perspective, and a supportive presence.

The results of this study also confirmed the findings from the Coleman, et al study (2005) that it is possible to determine the identity of people posting to the JHPCRC Web site even when specific information is not requested/required. It also confirmed that the posters to the PCNP, and those filling out the online survey, were predominantly family members. The high proportion of female posters/respondents is confirmed by other research that shows women tend to be more represented on online cancer support groups (Klemm et al., 2003; Lieberman et al., 2003; Lieberman, 2008)

The small number of patients posting to the PCNP, 6%, and the online survey, 15%, raises the question of whether pancreatic cancer patients would make much use of such an online resource. Other studies show similar low patient participation. One done among 800 newly-diagnosed cancer patients and 200 of their caregivers found that only 4.8% of patients, but 48% of caregivers, accessed the Internet for cancer information (James et al., 2007). However, half the patients used the information obtained by a loved one (Edwards et al., 2009). Another study of patients showed only 15% had ever read postings to an online support group and only 4% had ever posted to such a group (van Uden-Kraan et al., 2009). Predictors of online use were patients who were younger, more highly educated and employed (van Uden-Kraan et al., 2009). One additional factor in the low patient participation in the PCNP study may have been that the peak of incidence for pancreatic cancer is 60-80, an age group that is not yet using the Internet heavily (Pew Internet & American Life Project, 2009). This age trend was seen in a study of the number

of cancer survivor stories found on 3738 distinct Web sites. There older adults, men, and racial minorities were underrepresented on the analyzed sites (Eddens et al., 2009).

**Traffic data.** It is encouraging that half the visitors to the page came more than once and stayed for longer than they did for the overall JHPCRC Web site, 4:04 minutes vs. 1:20. Also, the bounce rate of 34.8% is considered “excellent” (Google Conversion University, 2008). This suggests that people who came to the PCNP page found it of interest/use. This was also reinforced in the responses to the online survey, where all said they would like the PCNP page to be an on-going service of the JHPCRC Web site and most would come to such a page a few times to daily. It seems there is group of participants who would access such a page on a regular basis.

The source for most of the PCNP Web page’s traffic came from the JHPCRC Web site, which is understandable since that is where participants would have heard of the PCNP resource. Were the PCNP Web page to become an on-going feature of the site, it is possible that more traffic could come from outside the site as people searching for palliative care or symptom information and pancreatic cancer could be directly referred. As it was, the PCNP resource was seen as a part of the JHPCRC service and seems to have reflected well upon the institution.

The primary source of traffic to the PCNP Web page from within the JHPRC site was the discussion board. This makes sense as that is a resource people use to find out about pancreatic cancer and its treatment, and so those on the discussion board would have been more likely to be interested in the PCNP service. The reminders on the discussion board throughout the study also probably helped direct traffic to the PCNP page over time. It is unclear how many of those posting questions and answers to the PCNP were also interacting with the discussion board. The archive of the discussion board shows hundreds of entries during the study period, whereas only 48 individuals posted questions or sent an email to the PCNP. In the future, the PCNP could

respond on the discussion board, but participants there may prefer that it is an unmoderated forum where healthcare providers are not actively involved. The email addresses for the JHPCRC physicians are listed on the Web site, but they do not receive many emails when compared to the volume of discussion board postings (Hruban, Herman, 2009).

As is often the case with online services, more people were reading the page than were posting to it (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). Of the 395 unique visitors, 12% (n=48) posted questions or emails to the PCNP. Some people were likely curious about the PCNP page and may not have had questions they needed or wanted to post. There is also data that lurkers to such sites derive some of the same benefits as those posting to them (van Uden-Kraan et al., 2008).

Interestingly, the traffic to the page was international with 11% of the visits coming from outside the U.S. (74 of 650 visits). While most of the foreign traffic came from English-speaking countries, 4% (n=27) came from countries in Scandinavia, South America, and Asia. This is important to recognize when responding to participants, as one cannot assume that aspects of pancreatic cancer care are comparable in other countries. It also speaks to the already global aspects of the Internet and the fact that people from around the world will seek out a helpful resource, regardless of their geographical location. This has implications for future Internet health services.

Finally, the fact that the largest volume of postings came in the first week, 39%, suggests a possible novelty affect. However, as the study ran over holidays where the traffic to the site and page was lower, it is not possible to determine what the volume might have been for a more regular time of year.

**Online survey.** The PCNP survey results suggested that reading the postings and responses was helpful and that people saw questions and answers they hadn't thought of. All

respondents felt the PCNP should be an on-going aspect of the JHPCRC, although this was not a surprising response since it was a free service and, again, those visiting the PCNP Web page and filling out the survey may have been more interested in such a resource.

The scores to the MOS suggest that respondents were more appreciative of the informational, rather than the emotional, support the PCNP provided. The lower scores and high “doesn’t apply” for the emotional questions suggest this may not be what they either expected or wanted from an online resource. This also suggests that there may be limits to the kind of things posted on a public site, although the postings/requests to the JHPCRC discussion board are occasionally quite candid and emotional. However, those are in the context of an online community where participants might feel they “know” one another over time as opposed to intermittent communication with a professional healthcare provider such as the PCNP.

The low response rate to this survey was disappointing as only 5% (n=20) of the total visitors to the PCNP Web page filled it out. This may have been for several reasons. As noted earlier, one might be the older age of those interested in information on pancreatic cancer. The majority of those completing the survey were middle-aged, which is a group that uses the Internet less than younger populations (Pew Internet & American Life Project, 2009). Then the link may not have been in the ideal location for people coming to the PCNP page to see (Survey Monkey, 2009). A Cochrane review done in 2009 suggests higher response rates to online surveys occur when participants receive incentives, pre-notices and/or follow-up communication about the survey or have the survey link emailed to them (Edwards et al., 2009). A 2000 meta-analysis of Internet-based surveys found a mean response rate of 39.6% (Cook, Heath, & Thompson, 2000). However, the analysis does not provide details on whether the online surveys were accessed by a link, an email, or some other method of notification or follow up. Neither the Cochrane review nor the 2000 meta-analysis focused uniquely on healthcare studies. In a trial of

a web-based nutritional intervention, only 8.9% of HMO members who were invited to participate completed the baseline survey (Stopponi et al., 2009). The odds of responding to the program were 10% lower for each decade of increased age (Stopponi et al., 2009).

**Postings to the PCNP.** Posters seemed comfortable sharing specific details of a patient's situation on a public forum. The supportive nature and responsiveness of the PCNP may have made them feel this was a real and trusted resource. The questions in the emails were of a similar nature as the publically posted ones, suggesting that no one took advantage of email as a way to get more personal or private information.

The postings and online interactions were very similar to those the PCNP has experienced with patients and families in real-life palliative care situations. Many of the same issues occurred: concerns about the implications of symptoms, uncertainty over prognosis, the lack of education of what to expect with end-stage pancreatic cancer or what dying looks like, issues around nutrition, especially as they related to patients being able to withstand chemotherapy and other life-prolonging treatment. These are typical issues for many caregivers regarding hospice or palliative care (Newton, Bell, Lambert, & Fearing, 2002). Some posters seemed focused on the numbers of the CA-19 tumor markers or to positive diagnostic findings despite clinical evidence to the contrary. Others seemed to be trying to find comfort in the fact that ambiguous or pending diagnostic testing had yet to confirm a diagnosis of pancreatic cancer.

Not surprisingly, given the conclusion of the Coleman et al study (2005), many posters did not seem to realize their family member was so ill or close to death (Coleman et al., 2005). In 37% (n=18) of the scenarios described, patients were more than likely to be at an end stage or actively dying. However, only a few of the postings acknowledged that. Other postings were still very focused on how to improve the patient's strength or nutritional status so as to survive

further treatment. This suggests an opportunity to provide education and palliative or hospice care to these families so that they can better prepare for death.

Most of those posting questions/emails were looking for factual information about pancreatic cancer, not necessarily that of palliative care. They repeatedly asked technical questions about pancreatic cancer and its treatment despite the PCNP confirming that that was not her area of expertise. The PCNP referred them consistently to other online or personal resources, like the PanCan or NIH hotline, so that they could get the information they were seeking. There seemed some resistance to hospice referrals, with posters acknowledging how hard it was to hear that hospice might have been appropriate.

**PCNP responses.** The positive feedback to the PCNP's responses, both on the public forum and via the online survey, was very encouraging. Participants seemed to appreciate the efforts the PCNP went to and to be very grateful for them. It took a little time for the PCNP to develop a pattern for responding. First, in order to insure that the information provided was accurate, the PCNP researched the answers to most of the posted questions and drafted a response. This response was then reviewed and edited by the PCNP to insure that it fully addressed the question being posed, as best as the PCNP could determine, and did so in a way that was accessible and succinct. As a result, the process of answering questions was somewhat time-consuming, particularly when people posted a question or topic with which the PCNP was unfamiliar.

The PCNP also sought to make referrals to a local resource whenever possible so that posters would have someone to turn to for more information. In some cases, posters did not realize how serious the issue was, as with the patient with breathing issues. In others, they already seemed inclined to follow up with a provider and may have only needed support for that. Hospice was a referral area that was initially made with hesitation given the posters' reluctance

as previously noted. However, over time it became clear that people were unaware their family member was in the last stage of pancreatic cancer and it therefore seemed appropriate for the PCNP to make this referral. Related to that were the five instances where the PCNP broke bad news about the prognosis or significance of a certain symptom. Again, this was done with some hesitation, yet it seemed that no one else might be giving the posters this information and that such an exchange would perhaps be of help to others reading the page. The lack of negative feedback about this on the online survey, either via comments posted to the PCNP, on the discussion board or to the online survey, suggests this may have been the case. Also, the email addresses for Dr. Wiegand and Dr. Hruban were posted on the PCNP page as research study resources, but neither was contacted during the study with any concerns or complaints.

Finally, it was somewhat unnerving to post responses, as the PCNP was very aware of the public nature and scrutiny of the dialogue. This became less of an issue over time, but never fully went away. There was a sense of a large responsibility to give appropriate, accurate information in a sensitive way, which added to the overall effort of responding.

### **Limitations**

The study has several limitations. The sample was small and not a randomized one. Therefore, generalizability is limited. The study's generalizability was also hampered by the validity threat of the Thanksgiving, Christmas, and New Year holidays. These certainly affected traffic to the PCNP page and could also have affected the concerns and nature of the postings.

There is the chance that some of the respondents who completed the online survey may not have actually had experience with the PCNP Web page. There were also some technical problems with the online survey. These were corrected after the seventh respondent, but may have affected some of the previous responses. It was also possible for some survey respondents to answer questions that were not appropriate, such as a respondent saying he/she had not posted

a question to the PCNP being able to answer questions about that experience. The response rate on the online survey was also low, both overall and to particular questions, so it is not possible to generalize those results.

A limitation with the traffic data is that it includes the researcher's visits. This could have affected the data of the time on the site and the bounce rate. The traffic to the PCNP Web page was also a small proportion of the total traffic to the JHPCRC site, but could possibly be increased by more direct participation on the discussion board or more references to the PCNP page, such as in the physician blogs or other sections of the Web site.

Finally, the researcher was also the intervention, which may have affected results of how the postings were distributed across the palliative care domains. The postings were analyzed individually, but they were part of a dialogue and it is that dialogue that participants coming to the PCNP page saw. Therefore, topics included in the PCNP's responses may have affected subsequent postings and therefore the dispersion across the palliative care domains. The PCNP also added key words to the postings at the suggestion of one survey respondent. This may have helped those coming to the PCNP page to better navigate to relevant postings, but could have affected the nature of issues raised in future posts.

## **Recommendations**

Palliative care content should be added to the JHPCRC Web site. Modules could be developed to address the key content areas included in the postings to the PCNP. Links should be clarified to the PanCan and NIH Cancer sites, and any other organizations that provide direct personal responses to the public so people coming to the JHPRCR are aware of these services. Finally, further study needs to be done on whether and how to provide the PCNP as an ongoing resource on the JHPCRC site. In the meantime, the postings and responses on the PCNP page are still available on the JHPCRC Web site, although the page is no longer interactive.

Beyond the PCNP page on the JHPCRC site, further research needs to be done on providing aspects of palliative care online. This could be done by some of the larger palliative care and hospice organizations. Local organizations could also have one of their providers available on the organization's Web site. Research should include participant outcomes so that financial assessments can be made of the value of such online resources.

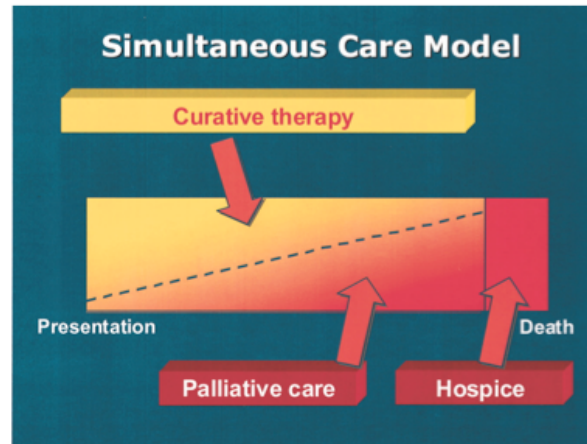
If future research confirms the value of such an online palliative care resource, then the additional issues of licensure and reimbursement will need to be addressed. This is likely something that will eventually happen as part of future healthcare changes. Physicians are already grappling with how to deal with email from patients and whether patients always need to be seen in person to address healthcare issues. Online health modalities will only become more prevalent as the Internet, and technologies to access it, proliferate.

### **Contribution project to personal leadership goals**

My personal leadership goal is to contribute to the palliative care field through practice, teaching, and research. As noted in the literature review, this project is unique and learnings from it will allow me to be a resource and leader in providing aspects of palliative care online. I plan to publish these results and have already applied to present them at upcoming conferences.

Figure 1

Fig 1. From Emanuel LL, von Gunten CF, Ferris FD (eds): The Education for Physicians on End-of-Life Care (EPEC) Curriculum



Meyers, F. J. et al. J Clin Oncol; 21:1412-1415 2003

## Appendix A

PICO: Patient/Population/Problem, Intervention, Comparison, Outcomes

Patients- Those with pancreatic cancer and their families coming to/posting to the Palliative Care Nurse Practitioner (PCNP) Web page on JHPCRC Web site.

Problem- Patients with pancreatic cancer and their families could benefit from palliative care services, but may not have access to them due to lack of referrals, awareness, or service availability. They come to the JHPCRC Web site, but are not presented with palliative care as a treatment option. The discussion board provides support in terms of patients and family members sharing with one another. However, professional healthcare providers do not monitor this board and so information there may not be appropriate or accurate.

Intervention-

1. Providing online interaction with a PCNP via a designated Web page on the JHPCRC Web site.
2. A public questions section on the PCNP Web page where people can post directly to the PCNP and read the responses in return.
3. The PCNP's email address for people to send private messages.

Comparison with other treatment- Postings on the discussion board or to the JHPCRC physicians when access to a PCNP is not available.

Outcomes

1. Number of visits to the PCNP Web page.
2. Number of posted questions/emails and qualitatively categorizing that data across the eight palliative care domains and any other themes.
3. Response to an online survey with information on demographics, Web page participation, and helpfulness of the PCNP intervention.

## Appendix B

## Nurse Practitioner Competencies in the Palliative Care of the Oncology Patient

1. Conducts comprehensive and/or problem-focused physical, emotional, social, cultural, and spiritual assessment of pain and other symptoms of patients and families experiencing life-limiting, progressive illness.
2. Orders, may perform, and interprets common screening and diagnostic tests based on the goals of care for palliative care patients.
3. Analyzes and interprets history, presenting symptoms, physical findings, and diagnostic information to formulate appropriate differential diagnoses for patients and families experiencing life-limiting, progressive illness.
4. Utilizes advanced knowledge and skills to assess physical, emotional, psychosocial, and spiritual/existential suffering in patients and families experiencing life-limiting, progressive illness.
5. Prioritizes health problems of patients and families experiencing life-limiting, progressive illness.
6. Identifies expected outcomes based on critical analysis of both complex assessment data and diagnosis that are relevant to the patient, family, and interdisciplinary/healthcare team and with consideration of risks, benefits, burden, and cost.
7. Applies relevant conceptual models, theories and research in developing, implementing, and evaluating comprehensive, effective, compassionate, and culturally sensitive plans of care across a variety of healthcare settings which promote health and manage life-limiting, progressive illness experienced by patients and families.
8. Prescribes/recommends medications to alleviate pain and other symptoms associated with life-limiting, progressive illness. Manages complex pain/symptoms utilizing research-based practice.

9. Manages and treats complex physical, emotional, social, and spiritual problems/needs of patients and families experiencing life-limiting, progressive illness by integrating appropriate nonpharmacologic and complementary/alternative therapies into the plan of care.

10. Provides guidance and counseling to patients and families regarding the management of life-limiting, progressive illness throughout the illness trajectory from time of diagnosis with advanced disease and into the bereavement period for families/survivors.

11. Identifies spiritual needs of patients and families and either addresses needs or refers for pastoral care.

12. Assumes responsibility for the overall evaluation, documentation, and communication of care to enhance continuity of palliative care across healthcare settings.

13. Accurately documents comprehensive or problem-focused palliative care of patients experiencing life-limiting, progressive illness, which allows for maximum reimbursement of services (Skalla, 2006).

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Appendix C

Online Facilitated Studies Summary and Evidence Grading \*

Author/ Year	Question	Design/ intervention	Sample	Results	Limitations	Rtg:
Barak, 2006	Do 4 factors correspond to participant and provider perceived helpfulness of online conversations with highly distressed individuals?	2 studies, both qualitative, conversations chosen randomly and evaluated by trained evaluators. Factors studied: depth and smoothness (session impact) positive and emotional arousal on client end-of-session mood, and various textual variables. Statistics on textual analysis	Study 1: 40 chat room conversations which clients said were helpful vs. 40 other chat conversations Study 2: evaluated moderators' perception of helpfulness for 60 chat room conversations	Study 1: 4 factors confirmed helpful vs. other conversations Study 2: 4 factors correlated with moderators' sense of helpfulness. Key ftrs: deep, smooth conversation, longer writing. These are similar in offline conversations	Qualitative, Summarizing 2 studies together confusing.	III B
Christen -sen, 2004	Efficacy 2 internet interventions for community-dwelling individuals with depressive sx?	RCT, one intervention was Website with psychoeducation, other offered cognitive behavior therapy (CBT). Control used attention placebo. All legs got weekly phone calls/reminders to use Web sites	Education leg: 165, CBT: 182, control 178	Both online interventions more effective than control at reducing depression sx. CBT more effective at improving dysfunctional thinking, but depression literacy as effective at reducing depression	Need 12 mth follow up to see if results sustained, facilitators were lay interviewers who only reminded participants, high dropout rate among CBT leg may affect results	I B
Gustaf- son, 2001	QOL impact of computer support system among breast cancer pts?	RCT, pre/post Soc supp/info new tool, participation measure tool, FACT-B QOL, CHES components	246 breast cancer pts, oversampling among underserved	After 5 months, intervention group had better social support and greater confidence than control. Benefits greater among underserved subsample.	Multifactorial interventions makes difficult to know what worked/didn't.	I B
Gustaf- son,	various	Review of CHES RCT studies with various inter-	Various. All with life-threatening	Using online system for information & analysis	Individual study specifics not always available	I B

Author/ Year	Question	Design/ intervention	Sample	Results	Limitations	Rtg:
2002		ventions including “ask expert” feature	illness: HIV, cancer, CAD	service contributed more to QOL than emotional support. Ask an expert results not singled out.		
Lorig, 2002	Will a listserv improve back pain and reduce costs?	RCT, Listserv moderated by professionals	580 people with back pain across 49 states	Participation in the listserv group improved health status and reduced hospital use	Multidimensional intervention, difficult to assess individual components	I B
Reger, 2008	NA	Meta-analysis of effects internet/computer-based cognitive behavioral therapy on anxiety	19 RCTs, 6 had therapist/ coach	Effects of internet-based treatment superior to placebo or waitlist.	Small sample sizes, rare use placebo controls, only 6 w/therapists/ providers	I B
Shaw, 2006	How women with breast cancer learn from an interactive computer system?	Descriptive, comparative (pre/post) CHES components	231 recently diagnosed low- income women with breast cancer	Information and interactive service helped increase perceived information confidence but communication services (discussion group expert resource) did not.	Self report was sole measure of learning, behavior measured by time on service categories, facilitator didn't take active role	III B
Wagner, 2006	Use of email with therapist as effective means to deliver therapy for complicated grief?	German RCT with email treatment vs. waiting list control condition. Pre/post measure of depression/ anxiety, mental and physi- cal health as sx cluster for complicated grief	Recruited online, only 25% remained for randomization: 29 treatment group, 26 control, avg age 37, 85% female, well educated, 64% had lost child	Treatment group had significant improvement and showed large treatment effect. Results maintained 3 months later	Sample skewed to mothers dealing with loss of child, no specific complicated grief tool, significant reduction vs. enrollment due to exclusion criteria and drop outs, Online recruiting /measures means sample maybe not representative	I C
Wagner, 2008**	Email as effective means to prevent complicated grief?	Swiss, pilot, pre-post study. Counselors corresponded with high-risk participants over 3 weeks across 7 modules.	35 individuals bereaved in previous 14 mos. Details NA	Intervention led to significant reduction in sx of complicated grief and depression at post-treatment	Pilot study, details NA	II-NA

Author/ Year	Question	Design/ intervention	Sample	Results	Limitations	Rtg:
Warmer- dam, 2007	Internet effective to treat depressive sx in adults?	Protocol for RCT, CBT, and problem solving therapy with email coaches, to treat analysis, measured pre/post depressive sx but also anxiety, qol, dysfunctional cognition, worrying, problem-solving skills, mastery, absence at work and use of healthcare	300 split across 2 treatment legs, waiting list control	Data NA but authors state internet-based problem-solving coaching may be viable alternate to treat depression as shorter/more flexible.	Article focused on protocol, not study results, selection bias as sample responded to ads in newspaper and online, timing 2 intervention legs not comparable	I- NA

- Level I: RCT, Meta-analysis
- Level II: quasi-experimental
- Level III: non-experimental, qualitative, meta-synthesis.
- Quality of evidence: A: high, B: good, C: low/major flaw

# Ask a Nurse Practitioner About Symptoms, Problems, Concerns

## 1. Ask a Nurse Practitioner on the Johns Hopkins Pancreatic Cancer Web site

You are invited to take part in a research study. You must be 18 or older to participate. The purpose of this study is to 1) learn about having a nurse practitioner answer questions about symptoms, medical problems, emotional concerns and other palliative care issues on this Web site; 2) see what kinds of palliative care questions people coming to this Web site have; and 3) see if such a palliative care resource is helpful.

By filling out this survey, you are agreeing to participate in the study. Your participation is voluntary. You will not be asked for any information that will identify you. There may or may not be a benefit to you in participating in the study. The study is not likely to cause any potential risks.

Please fill this survey out only after you've spent some time on the "Ask a Nurse Practitioner About Symptoms, Problems, Concerns" Web page. We are interested in your comments and experience with the palliative care nurse. Please click on the appropriate answer for each of the following questions. Thank you for participating!

### 1. Is this the first time that you have come to the "Ask a Nurse Practitioner About Symptoms, Problems, Concerns" Web page?

- A. Yes
- B. No

### 2. If no, how often have you come to the "Ask a Nurse Practitioner About Symptoms, Problems, Concerns" Web page?

- A. Only once
- B. 2-5 times
- C. 5-10 times
- D. More than 10 times

### 3. Have you ever posted a question or comment to the Web page or sent the palliative care nurse practitioner an email?

- A. Yes
- B. No

### 4. Your sex is

- A. Male
- B. Female

# Ask a Nurse Practitioner About Symptoms, Problems, Concerns

## 5. Your age is

- A. 18-29
- B. 30-39
- C. 40-49
- D. 50-59
- E. 60-69
- F. 70-79
- G. 80 and above

## 6. With which racial/ethnic group do you identify yourself?

- A. White
- B. Black
- C. Hispanic/Latin
- D. Asian
- E. Multiracial
- F. Other (please specify)

## 7. What is the highest level of school you have completed?

- A. Elementary or grade school
- B. High School
- C. College
- D. Graduate/ professional school



# Ask a Nurse Practitioner About Symptoms, Problems, Concerns

**10. Please click on the best answer to the following questions:**

	Not helpful	Uncertain	Somewhat helpful	Helpful	Very helpful	Doesn't apply
How helpful was reading other people's posted questions and comments on the "Ask a Nurse Practitioner about Symptoms, Problems, Concerns" Web page?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How helpful was any communication you personally had with the nurse practitioner?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**11. Do you think having a resource like the palliative care nurse practitioner on the Johns Hopkins Pancreatic Cancer Web site would be helpful on an on-going basis?**

- A. Yes
- B. No

**12. If yes, how often do you think you might come to the "Ask a Nurse Practitioner About Symptoms, Problems, Concerns" Web page?**

- A. Once or twice
- B. A few times
- C. Daily

**13. What did you like most about the "Ask a Nurse Practitioner About Symptoms, Problems, Concerns" resource?**

**14. What did you like least about the "Ask a Nurse Practitioner About Symptoms, Problems, Concerns" resource?**

## Ask a Nurse Practitioner About Symptoms, Problems, Concerns

**15. How could we improve the "Ask a Nurse Practitioner About Symptoms, Problems, Concerns" resource?**



# Ask a Nurse Practitioner About Symptoms, Problems, Concerns

## 2. Contact information

If you have any questions about the study, please contact Dr. Debra Wiegand at [wiegand@son.umaryland.edu](mailto:wiegand@son.umaryland.edu), or Dr. Ralph Hruban at [hurban@jhmi.edu](mailto:hurban@jhmi.edu). Thank you for your participation.

## Appendix E

## Johns Hopkins Pancreatic Cancer Research Center Web site Homepage

Pancreatic Cancer Center at Johns Hopkins - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Refresh Home Search Favorites

Address <http://www.path.jhu.edu/pancreas/> Go

Home | Donate | Discussion Board | Blog | Search



**JOHNS HOPKINS**  
MEDICINE



The Sol Goldman Pancreatic Cancer Research Center

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**WHAT'S NEW**  
Pancreatic Cancer News

April 2009

**DNA Changes Caused By Smoking**

Scientists at the Sol Goldman Pancreatic Cancer Research Center at Johns Hopkins report in the April 15th issue of Cancer Research (Cancer Research volume 69, pages 3681-3688, 2009) that up to 25% of the genetic mutations found in pancreatic cancers from cigarette smokers are caused by cigarette smoking.

[Read more...](#)

**Experience Treating Pancreatic Cancer is Important**

Studies show that patient outcome is best at high volume surgical centers. Surgeons at Johns Hopkins performed more pancreatic cancer resections than any other institution in the world.



Year	Number of Resections
1994	62
1995	74
1996	124
1997	161
1998	188
1999	227
2000	260
2001	292
2002	328
2003	367
2004	408
2005	450
2006	492
2007	534

**For Patients and Family**



Johns Hopkins is a world leader in pancreatic cancer treatment, diagnosis, and symptom evaluation. Learn about everything you need to know about Pancreatic Cancer and Johns Hopkins' research and how we can help. [Click here to learn more....](#)

**Pancreas Multidisciplinary Cancer Clinic**



The Johns Hopkins Pancreas Multidisciplinary Cancer Clinic is designed to evaluate patients with known or suspected pancreatic cancer. The clinic is committed to a single day comprehensive evaluation of a patient incorporating all the resources available for the education, diagnosis, treatment and research of pancreatic cancer by some of the top pancreatic cancer clinicians and specialists in the country. [Click to learn more....](#)

**Advocates & Donors**



Donate to our Pancreatic Cancer Research, Raise Awareness, Become Involved and Spread the Word. Private giving has provided us with the opportunity to make real advances in our understanding of pancreas cancer and it has provided critical support to our young investigators. Please consider supporting our research. [Click to learn more....](#)

**For Medical Professionals**



This section is for health care professionals and provides information on our patient care, pancreatic cancer team, our research, and educational materials. Learn about referring patients, getting a

start

Inbox - Microsoft Out... SmartZone Communic... Pancreatic Cancer Ce... Document3 - Microsof...

Internet

3:41

## Appendix F

## Patient and Family Web page on JHPRCR Web site


Pancreatic Cancer - Johns Hopkins Medicine: Our Pledge to You - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Refresh Print Mail Stop

Address http://www.path.jhu.edu/pancreas/pledge.php

Home | Donate | Discussion Board | Blog | Search



**JOHNS HOPKINS**  
MEDICINE

The Sol Goldman Pancreatic Cancer Research Center

Expand All | Collapse All

### Johns Hopkins & You

- [Our Pledge to You](#)
- [Choosing Johns Hopkins](#)
- [Evaluating My Case](#)
- [Becoming a Hopkins Patient](#)
- [Pancreas Multidisciplinary Cancer Clinic](#)
- [Participating in Research](#)
- [Supporting Research](#)
- [Raising Awareness](#)
- [Our Blog](#)

### Patient Education

- [Basics of Pancreatic Cancer](#)
- [Diagnosis](#)
- [Treatment and Care](#)
- [Intraductal Papillary Mucinous Neoplasms](#)
- [Islet Cell Tumors & Endocrine Neoplasms of the Pancreas](#)
- [Research Presentations](#)
- [Bibliography](#)
- [Other Pancreas Sites](#)

### Support Services & Research

- [Support](#)
- [Research](#)
- [Discussion Board](#)

### Our Pledge to You



This Web site is the culmination of a vast amount of knowledge, experience, and care compiled by the experts in pancreatic disease at the Johns Hopkins Medical Institutions. The content in this site represents over 20 years of cutting-edge treatment and research performed at this institution. The [Johns Hopkins Hospital was ranked as the overall best hospital in the United States in 2007 by U.S. News and World Report.](#)

We encourage you to contact our 28 doctors who have dedicated their careers to fighting pancreas cancer. These 28 doctors, including surgeons, medical oncologists, radiation oncologists, pathologists, gastroenterologists, radiologists, and a geneticist, are supported by an even larger group of scientists, nurse practitioners, and physician assistants. They are highly experienced at taking care of patients with pancreatic diseases because of the large numbers of patients that visit our institution from all over the world. Many studies, especially those involving surgical patients, have linked the outcome of therapy for a particular disease to the volume of patients treated for that disease. These studies have demonstrated that high volume centers have the best outcomes with the lowest rates of complications following treatment.

In 2005, [more than 240 Whipple procedures](#) (pancreaticoduodenectomies) were performed at Johns Hopkins which is an operation used to remove cancers and other diseases involving the head of the pancreas. This is more than any other center in the United States. We have performed over 3,000 Whipple operations over the past 25 years.

When you access us through one of our coordinators, she will try to determine how you can most successfully and efficiently be treated. Depending on the imaging and other tests that you have already had, we may elect to perform further diagnostic testing at this institution. We often perform a [three-dimensional CT scan](#) dedicated to the pancreas on a state-of-the-art 64-detector scanner which gives great detail. These images allow the treating team to visualize the pancreas and the nearby blood vessels and structures in fine detail to help plan further therapy. Sometimes, patients benefit from our gastroenterologists performing an [endoscopic ultrasound](#) examination of the pancreas during which an ultrasound probe (similar to a sonar on a submarine) is placed into the stomach to visualize the pancreas.

If you are diagnosed with or are suspected of having pancreas cancer, it is important to determine whether the disease has spread out of the pancreas to other organs and whether the disease can be surgically removed. The disease cannot be surgically removed if it substantially involves the major blood vessels that run near the pancreas.

- [If the disease has not spread to other organs and appears surgically removable](#), a surgeon will coordinate your care initially and will make arrangements for your surgery.
- [If the disease has spread to other organs and does not appear to be removable](#), a medical oncologist (chemotherapy doctor) will coordinate your care initially, sometimes with a radiation oncologist.
- [If treatment options are not clear](#), our clinic may provide a multi-disciplinary evaluation of your care based on the highest standards of care.

**We encourage you to contact our referral coordinator at 410-933-PANC (410-933-7262).**

She will help you determine whom you should see first and how we can best help you. She will schedule your appointment within a week. We encourage you to take advantage of our tremendous experience in caring for patients with pancreatic diseases. It is extremely important that you choose a team of specialists with the most up to date knowledge, broad experience, and compassion. We pledge to take great care of you.

Internet

start | Inbox - Microsoft ... | SmartZone Comm... | Removable Disk (F:) | cap proposal [Com... | Pandora Radio - Li... | Pancreatic Cancer... | 4:10 PM

## Appendix G

## PCNP Web Page

Grab File Edit Capture Window Help

Ask a Nurse Practitioner » Welcome!

jhu.edu https://apps.pathology.jhu.edu/care/?page\_id=2

Most Visited Amazon eBay Weather Blackboard Library Microsoft Exchange ... Novell WebAccess SurveyMonkey - Log... Ask a Nurse Practitioner

Ask a Nurse Practitioner » Welcome!

## Ask a Nurse Practitioner

About Symptoms, Problems, and Concerns

### Welcome!

This Web page was part of a research study to learn if having a nurse practitioner answer questions on this Web site is helpful. The study ended on January 4th but the attached link will take you to the page with the posted questions and answers. Previous analysis of the discussion board showed common questions about symptoms, medical problems, and emotional concerns. These are aspects of palliative care, an emerging field focused on improving the quality of life for people with serious illness and their families. What is learned from this study will be used to improve this Web site and published so that other cancer sites can consider adding such services.

**What is palliative care?**  
Palliative care focuses on treating pain, stress, and other symptoms of serious illness. Palliative care doesn't depend on prognosis and can be given at the same time as treatment meant to cure. The goal of palliative care is to relieve suffering and provide the best possible quality of life for patients and families.

Search

**Links**

- » [1. View posted questions answers](#)
- » [2. About the Study](#)

Done

## Appendix H

## Examples of PCNP dialogue on Web page

The screenshot shows a web browser window with the following elements:

- Browser Menu:** Grab, File, Edit, Capture, Window, Help.
- Address Bar:** Ask a Nurse Practitioner » Blog Archive » Previously Ask a Question. URL: <https://apps.pathology.jhu.edu/care/?p=1&cp=all#comments>
- Navigation:** Back, Forward, Home, Reload, Stop, Print, Search.
- Bookmarks:** Most Visited, Amazon, eBay, Weather, Blackboard, Library, Microsoft Exchange..., Novell WebAccess, SurveyMonkey - Log..., Ask a Nurse Practiti..., Google Calendar.
- Page Title:** 99 Responses to "Previously Ask a Question"
- Response 1:**
  - Author:** Mary Says
  - Date:** November 9th, 2009 at 7:49 pm
  - Key words:** bone pain, Neulasta
  - Text:** My husband is on chemotherapy. He actually does well until about 3 days after when he develops "bone pain" I believe from the Neulasta injection. He is going back to work tomorrow and obviously would not be able to take any narcotics for the pain while working, what else would you suggest for this pain? thank you.
- Response 2:**
  - Author:** mgrant1 Says
  - Date:** November 9th, 2009 at 8:58 pm
  - Text:** The package insert for Neulasta, available online at <http://www.neulasta.com/patient/support/support.jsp>, says "In a clinical study, mild to moderate bone pain occurred in 31% of the patients taking Neulasta® .... In most cases, bone pain was controlled with a non-narcotic pain reliever, such as acetaminophen." However, your husband should discuss the bone pain with his oncologist to confirm what would be best for him to take for it. Good luck!
- Response 3:**
  - Author:** Tammy Says
  - Date:** November 9th, 2009 at 9:17 pm
  - Key words:** diagnosing pancreatic cancer
  - Text:** My aunt was just told today that she has cancer on both sides of her liver and also in her pancreas. They want to do more tests to see where the cancer began. They cannot operate on the liver and she cannot take radiation. What other options might she have if any??
- Response 4:**
  - Author:** mgrant1 Says
  - Date:** November 9th, 2009 at 9:40 pm
  - Text:** It's hard to know exactly what tests they are referring to, but one option is to get a sample of tissue (called a biopsy) from the liver or pancreas. That can be done sometimes without operating by inserting a needle from outside of the abdomen and guiding it to where the cancer is. The cancer team will need to know what kind of cancer it is/where it came from since that will determine what kind of treatment is most

## Appendix I

### Internet Definitions

**Blog (short for Web log):** A Web log is usually defined as a personal or noncommercial Web site that uses a dated log format (usually with the most recent at the top of the page) and contains links to other Web sites along with commentary about those sites. A Web log is updated frequently and sometimes groups links by specific subjects, such as politics, news, pop culture, or computers.

**Chat room or discussion board:** An interactive forum where you can “talk” in real-time. The chat room is the place or location online where the chat is taking place.

**Comment:** Real-time communication over the Internet. You type and send messages that appear almost instantly on the computer monitors of the other people who are participating in the comment area.

**Download:** Putting information on your computer. You can download information from the Internet, discs or CDs, and other computers.

**E-Mail (electronic mail):** A service that allows people to send messages with pictures and sounds from their computer to any other computer in the world. To send someone an e-mail message you need an e-mail account and to know the other person's e-mail address. (For example the researcher’s email at the Johns Hopkins University School of Nursing is [mgrant1@son.jhmil.edu](mailto:mgrant1@son.jhmil.edu).)

**Internet:** A network of millions of computers from all over the world. The Internet allows computers to trade information using telephone lines, fiber-optic cables, and satellite links. It is also referred to as the "Net."

**Internet Service Provider (ISP):** A company that provides Internet access to customers.

**Link:** a highlighted and underlined word or phrase on a Web page. By clicking on a link, you can "jump" to a new Web page or a completely different Web site. When you move the cursor over a link in a Web page, the arrow will turn into a little hand, letting you know that it is a link.

**Login:** The process of identifying oneself to a computer, usually by entering one's username and password.

**Navigate:** The act of moving from page to page and Web site to Web site online. It is also called browsing or surfing.

**Online:** Another way to describe having access to the Internet or actively using the Internet.

**Post:** To leave a message in a comment area or discussion board.

**Search Engine:** A program that searches information on the World Wide Web by looking for specific keywords and returns a list of information found on that topic. Google at [www.google.com](http://www.google.com) is an example of a search engine.

**Social Networking Site:** A Web site specifically focused on the building and verifying of social networks for whatever purpose. Many social networking services are also blog-hosting services.

**Traffic:** The amount of visits a Web site receives. The following types of information are often collated when monitoring Web traffic:

- \* The number of visitors.

- \* The average number of page views per visitor – a high number would indicate that the average visitors go deep inside the site, possibly because they like it or find it useful. Conversely, it could indicate an inability to find desired information easily.

\* Average visit duration – the total length of a user's visit

\* Average page duration – how long a page is viewed for

Uniform Resource Locator (URL): The specific location or address of material on the Internet. For example the URL for the JHPCRC page is <http://pathology.jhu.edu/pancreas/>.

User: Refers to anyone who uses a computer. Another way of saying "User" is "Netizen."

Web site: A collection of "pages" or files linked together and available on the World Wide Web.

Web Page: A page or file on a "Web site".

Webmaster: The person responsible for administering a Web site.

World Wide Web: An infinite number of games, Web sites, pictures, sounds, stories, and other things all connected to each other through links on the Internet. You can "surf" the Web through your browser and find information about virtually anything. The Web is just one service on the Internet. Other services on the Internet include Internet relay chat, newsgroups, and e-mail. Web sites on the World Wide Web have "www" in their address

Based on ("Internet definitions," No date)

## Appendix J

## Announcement about PCNP Web Page

Grab File Edit Capture Window Help

Pancreatic Cancer News

http://pathology.jhu.edu/pancreas/news2009.php

Most Visited Amazon eBay Weather Blackboard Library Microsoft Exchange ... Novell WebAccess SurveyMonkey - Log... Ask a Nurse Practiti... Google Calendar

Pancreatic Cancer News

Home Donate Discussion Board Search

**JOHNS HOPKINS**  
MEDICINE

**The Sol Goldman Pancreatic Cancer Research Center**

For Patients & Family Multidisciplinary Clinic NFPTR For Medical Professionals Donate Blog

Expand All Collapse All

**Johns Hopkins & You**


- Our Pledge to You
- ▼ Choosing Johns Hopkins
- ▼ Evaluating My Case
- ▼ Becoming a Hopkins Patient
  - Pancreas Multidisciplinary Cancer Clinic
- ▼ Participating in Research
  - Supporting Research
  - Raising Awareness
  - Our Blog

**Patient Education**

- Pancreas News
- ▼ Basics of Pancreatic Cancer
- ▼ Diagnosis
- ▼ Treatment and Care
  - Intraductal Papillary Mucinous Neoplasms
  - Islet Cell Tumors & Endocrine Neoplasms of the Pancreas
- Research Presentations
- Bibliography
- Other Pancreas Sites

**What's New 2009**

**Ask a Nurse Practitioner About Symptoms, Problems, Concerns November 2009**



There is a [new section](#) that we've added to this Web site. It is part of a research study to learn if having a nurse practitioner answer questions about symptoms, medical problems, emotional concerns, and other palliative care issues on this site is helpful.

What is palliative care? Palliative care focuses on treating pain, stress, and other symptoms of serious illness. Palliative care doesn't depend on prognosis and can be given at the same time as treatment meant to cure. The goal is to relieve suffering and provide the best possible quality of life for patients and families.

What is a nurse practitioner? A nurse practitioner is a registered nurse with advanced training and a master's degree in nursing. Nurse practitioners work as primary care providers or in hospitals.

The nurse practitioner on this Web site, [Marian Grant](#), will offer information, education, and other support for people pancreatic cancer and their families. She is certified in palliative care and has a master's in nursing from the Johns Hopkins University School of Nursing. She has practiced as a palliative care nurse practitioner in one of the Johns Hopkins hospitals. She is currently completing a doctor of nursing practice program at the University of Maryland.

**News Archive**

- 2009
- 2008
- 2007
- 2006
- 2005
- 2004
- 2003
- 2002
- 2001
- 2000
- 1999
- 1998
- 1997
- 1996

Done

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Table 1

*Average score for MOSS social support tool*

The palliative care nurse practitioner is:	All	Posters	Non-Posters	Pa-tients	Spouse	Child	Age <50	Age >50	High School	College+
Someone you can count on to listen to you when you need to talk.*	4.13	5.00	3.83	5.00	4.00	4.00	4.67	3.80	4.50	4.00
Someone to give you information to help you understand a situation.*	4.50	5.00	4.27	4.00	4.25	4.75	4.50	4.50	4.00	4.67
Someone to give you advice about a crisis.*	3.78	4.50	3.57	3.00	4.00	3.75	4.00	3.60	3.50	3.86
Someone whose advice you really want.*	4.55	5.00	4.38	3.00	4.00	5.00	4.20	4.83	4.00	4.67
Someone to share your more private worries and fears with.*	3.30	4.50	3.00	3.50	2.75	3.75	3.00	3.50	4.00	3.13
Someone who understands your problems.*	4.42	5.00	4.13	4.00	4.00	4.63	4.75	4.25	4.00	4.50
How helpful was reading other people's posted questions and comments on the palliative care nurse practitioner webpage?	4.13	4.40	4.00	4.00	3.40	4.50	4.00	4.25	4.20	4.09
How helpful was any communication you personally had with the palliative care nurse practitioner?***	4.80	5.00	NA	NA	4.67	5.00	4.50	5.00	5.00	4.67

\* none of the time to all of the time, \*\* not helpful to very helpful

Table 2

*Postings to the PCNP by domain*

Palliative Care Domains	# Total	# Primary	# Secondary
1. Structure and processes of care	8	1	7
2. Physical aspects of care	30	23	7
3. Psychological and psychiatric aspects of care	16	6	10
4. Social aspects of care	3	0	3
5. Spiritual, religious and existential aspects of care	0	0	0
6. Cultural aspects of care	0	0	0
7. Care of the imminently dying patient	1	1	0
8. Ethical and legal aspects of care	3	0	3
9. Other/ non palliative care	31	24	7
Total	92	55	37