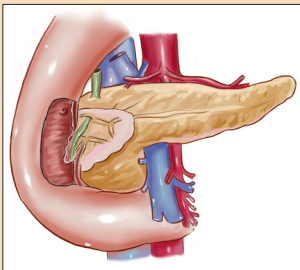


Caring for the Continuum of Patients With Pancreatic Cancer: The Importance of Survivorship Care Planning

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Background: Pancreatic cancer is widely recognized as one of the most formidable cancer diagnoses. However, whether aggressive treatment is undertaken or not, it is critical for all care providers to understand the treatment plan. Survivorship care plans are a new trend in improving communication between the providers and the patient.

Objectives: The current article will outline the pathophysiology, risk factors, diagnosis and prognosis, treatment, and potential complications of pancreatic cancer.

Methods: The importance of survivorship care planning will be demonstrated through a case study presentation and evidence-based discussion. In addition, a general template for a survivorship care plan has been included.

Findings: Based on a review of current literature and recommendations, it can be concluded that survivorship care planning would be beneficial for all patients with cancer. This simple tool has the potential to improve coordination of care and patient satisfaction.

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Cancer is the second leading cause of death in the United States (Centers for Disease Control and Prevention, 2010). Pancreatic cancer represents only 2.7% of new cancer diagnoses, but it is the fourth leading cause of cancer death within the United States (Torgerson & Wiebe, 2013). Pancreatic cancer is an aggressive form of cancer with an average five-year survival rate of 6% (Torgerson & Wiebe, 2013). In 2014, an estimated 46,420 new cases of pancreatic cancer were diagnosed, and about 39,590 people died of the disease (National Cancer Institute, 2014). Survivorship can be defined as the process of living with, through, and beyond cancer (Morgan, 2009). Although substantial progress has been made in understanding the biology of pancreatic cancer, structured survivorship care planning is still lacking in practice (Morgan, 2009).

Pathophysiology

The pancreas is a complex organ made of exocrine and endocrine glands. The exocrine glands release pancreatic enzymes

into the duodenum that help to digest foods. The endocrine cells release insulin and glucagon into the bloodstream to regulate blood glucose. More than 95% of the cells in the pancreas are exocrine glands, and exocrine tumors (adenocarcinomas) are the most common type of pancreatic cancer (American Cancer Society, 2014). Pancreatic adenocarcinomas evolve through alterations of noninvasive precursor lesions, typically pancreatic intraepithelial neoplasias (Vincent, Herman, Schulick, Hruban, & Goggins, 2011).

Risk Factors

Pancreatic cancer can result from genetic or environmental factors (MacIntyre, 2011). Unmodifiable risk factors include male gender, advanced age, African American race, family history of pancreatic cancer, and chronic pancreatitis (Broudo, 2010). Potentially modifiable risk factors include obesity, sedentary lifestyle, poor dietary intake, diabetes mellitus, cirrhosis of the liver, cigarette smoking, and possibly alcohol consumption

(Hayes, 2012). Tobacco abuse remains the single most reversible risk factor for pancreatic cancer (American Cancer Society, 2014).

Diagnosis

Diagnosis is often difficult because of a vague presentation of signs and symptoms. The most common of these include unexplained weight loss, painless obstructive jaundice, and depression (Hayes, 2012). Late signs of the disease may include pain, ascites, and deep vein thrombosis, which are often present after the patient has advanced or metastatic disease (Broudo, 2010).

Unfortunately, reliable screening methods for early detection do not exist, and invasive surgical resection is the only chance at long-term survival (Hayes, 2012). Once the cancer has metastasized, the patient is not considered a surgical candidate (Hayes, 2012). According to Hayes (2012), only 15% of patients have a surgically resectable pathology at the time of diagnosis.

A computed tomography (CT) scan with contrast is the gold standard for identifying pancreatic cancer, and magnetic resonance imaging can be used to stage the disease (MacIntyre, 2011). A biopsy is frequently obtained to assist in making the diagnosis (MacIntyre, 2011), but it is not always necessary or definitive (Vincent et al., 2011).

Treatment

Treatment planning for patients with pancreatic cancer usually includes individualized measures that simultaneously aim at tumor response and symptom management. Treatment may involve surgical resection, anticancer therapy with chemotherapy and radiation therapy, supportive care, and toxicity management (Campen, Dragovich, & Baker, 2011). Surgical resection is preferred if the patient is a candidate because it is the only chance for curative treatment. In addition, adjuvant therapy with chemotherapy and radiation therapy before or after resection has been shown to lengthen average survival time from 11 months to 20 months (Campen et al., 2011). If the diagnosis is made when the cancer is locally advanced, unresectable, or metastatic, the goals of therapy are then concentrated on maintaining quality life and providing symptom management (Campen et al., 2011).

Potential Complications

Complications of pancreatic cancer and its treatment may involve biliary obstruction, venous thromboembolism, pain, gastric outlet obstruction, pancreatic exocrine insufficiency, anorexia or cachexia, and depression (Torgerson & Wiebe, 2013). Supportive treatment is necessary to manage these complications. For example, biliary stenting may be required to treat biliary obstruction, or surgery may be needed to combat a gastric outlet or intestinal obstruction (American Cancer Society, 2014).

The emotional toll of this diagnosis and involved treatment can cause patients to feel overwhelmed and depressed. Depression was found in 33%–70% of patients with pancreatic cancer (Torgerson & Wiebe, 2013). According to Wolfgang et al. (2013), patients who are depressed are less likely to have their cancers managed optimally compared to patients who are not depressed.

Because of the nature of the disease and the vast number of possible complications, having a multidisciplinary team is beneficial (Elnahal, Pronovost, & Herman, 2013). Based on the individual's needs, this team may include surgeons, oncologists, radiation oncologists, gastroenterologists, pain management and palliative care experts, dietitians, psychologists or psychiatrists, social workers, and primary care providers (Pawlik et al., 2008).

Importance of Survivorship Care Planning

A care plan allows each member of the team to be aware of the plan of care, treatment progress, and future needs (Birken, Deal, Mayer, & Weiner, 2014). A written document can provide patients with a sense of comfort by having a plan for battling their disease (Tevaarwek et al., 2014). The following case study will provide an example of a patient with pancreatic cancer and will be followed by an example of a survivorship care plan.

Case Study

Mr. A., a 40-year-old man, presented to his local emergency department complaining of right upper quadrant abdominal pain and jaundice. A CT scan demonstrated cholelithiasis with intra- and extra-hepatic dilatation, as well as common bile duct dilation to 2.2 cm in greatest diameter all the way to the ampulla, and possible choledochocoele. Magnetic resonance cholangiopancreatography redemonstrated intra- and extra-hepatic bile duct dilatation, common bile duct dilatation, and choledochocoele. Common bile duct stones were also seen. Endoscopic ultrasound scan and endoscopic retrograde cholangiopancreatography with sphincterotomy revealed a mass possibly representing a choledochocoele or adenoma at the ampulla, and

TABLE 1. ECOG Performance Status

Grade	Description
0	Fully active, able to carry on all predisease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature (e.g., light house work, office work)
2	Ambulatory and capable of all self-care but unable to carry out any work activities, up and about more than 50% of waking hours
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
4	Completely disabled, cannot carry out any self-care, totally confined to bed or chair
5	Dead

ECOG—Eastern Cooperative Oncology Group

Note. From "Toxicity and Response Criteria of the Eastern Cooperative Oncology Group," by M.M. Oken, R.H. Creech, D.C. Tormey, J. Horton, T.E. Davis, E.T. McFadden, and P.P. Carbone, 1982, *American Journal of Clinical Oncology*, 5, pp. 649–655.

significant ductal dilation was seen proximally. During biopsy, surgical pathology revealed pancreatic adenocarcinoma, which was found to be stage I. About one month later, Mr. A. had a pancreaticoduodenectomy (Whipple procedure) and liver wedge biopsy. No complications arose from surgery.

Mr. A. has a significant past medical history including gastric reflux, clear cell kidney cancer (1999), current tobacco abuse (32 pack-years), and anxiety. He reports minimal alcohol use. He has no relevant family history and is married with two adult children. He is established with a primary care physician.

Mr. A. is in clinic today to see his surgical oncologist and has agreed to speak to the nurse practitioner (NP) about survivorship issues. He reports fatigue, anxiety, irritability, and mood swings. He denies abdominal pain or other physical symptoms. His physical examination findings are normal. Mr. A.'s top three stressors are coping, finances, and tobacco cessation. He has an Eastern Cooperative Oncology Group (ECOG) Performance Status score of 1. An ECOG grade 1 correlates with patients who are restricted in physically strenuous activity but are ambulatory and able to carry out work of a light or sedentary nature (ECOG, 2006) (see Table 1). This is related to his self-reported pain of 8 out of 10 and fatigue rating of 9 out of 10 in the past week. Specifically identified causes of psychosocial distress are uncertainty, feeling down, worry, loss of interest, coping with physical limitations, anger, loss of hope, feeling like a burden, appearance, feeling overwhelmed, spiritual concerns, lack of social support, difficulty concentrating, nausea, decreased energy, lack of appetite, weakness, weight loss, feeling drowsy, cramping, tobacco cessation, and filing for social security disability.

For his emotional health, he was referred to a psycho-oncologist. Financially, he lost his Medicaid insurance a few months ago, which continues to be a stressor. However, his daughter lives at home and helps out financially. He does not wish to speak with a financial counselor at this time. In terms of tobacco cessation, Mr. A. has a desire to quit but is struggling. He is agreeable to speaking with his primary care physician about trying a patch. The surgical oncologist gave him a prescription for metoclopramide to help his nausea. Education was provided on survivorship resources, definitions, and programs. He was referred to a medical oncologist for assessment and potential chemotherapy. He will follow-up with his surgical oncologist and the survivorship NP in four weeks.

Survivorship Care Planning in Practice

Survivorship care begins with a provider-initiated assessment. The National Comprehensive Cancer Network ([NCCN], 2014) survivorship guidelines provide a structure for addressing eight key health and wellness topics as they pertain to cancer survivors. The general categories of interest include anxiety and depression, cognitive function, exercise, fatigue, immunizations and infections, pain, sexual function, and sleep disorders (NCCN, 2014). The results of the assessment can then be used to develop a care plan.

Morgan (2009) stated that a survivorship care plan should include summarization of treatment received, possible side effects, screening, and health maintenance. In addition to managing active cancer treatment, providers must identify and address

General Information

Patient name: _____
Medical record number: _____
Phone (home): _____
Phone (cell): _____
Email: _____
Date of birth: _____
Age at diagnosis: _____
Support contact: _____

Care Team

Hematologist or oncologist: _____
Surgeon: _____
Primary care provider: _____
Nurse or nurse practitioner: _____
Mental health or social worker: _____

Background Information

Signs and symptoms: _____
Other health concerns: _____
Current tobacco use: _____
Diagnosis date: _____
New or recurrent cancer diagnosis: _____

Staging Study

List dates and findings of all staging studies (e.g., computed tomography scan).

Treatment Plan and Summary

Include when, how often, and coordinating provider.

Height: _____
Weight: _____
Body mass index: _____
ECOG Performance Status: _____
Treatment on clinical trial: _____
Surgery: _____
Surgical procedure: _____
Tumor type and grade: _____
Radiation therapy: _____
Chemotherapy: _____

Treatment Plan and Summary

Medical oncology visits: _____
Surgical oncology visits: _____
Laboratory testing: _____
Imaging: _____
Psycho-oncologist: _____

Needs or Concerns

Symptoms to watch for: _____
Prevention and wellness: _____
Financial advice or assistance: _____

Referrals Provided

Smoking cessation counselor: _____
Psychiatrist: _____
Social worker: _____

ECOG—Eastern Cooperative Oncology Group

FIGURE 1. Survivorship Care Plan Example

Note. From "Survivorship Care Plan Builder," by Journey Forward, 2015. Retrieved from <http://www.journeyforward.org/professionals/survivorship-care-plan-builder>. Copyright 2015 by Journey Forward. Adapted with permission.

Implications for Practice

- ▶ Improve provider communication by creating a collaborative care plan.
- ▶ Detect side effects and complications of therapy by incorporating a simple questionnaire into every clinic visit.
- ▶ Empower patients and caregivers to take an active role in their cancer care.

primary and secondary preventive care for cancer survivors (Robin Yabroff et al., 2013).

Although proven benefits (Tevaarwek et al., 2014) of survivorship care planning exist, one study (Birken et al., 2014) assessed 36 cancer programs and concluded that only one of those programs successfully developed and distributed the care plan to the patient and the primary care provider. One possible barrier to the adoption of the Institute of Medicine recommendation (Hewitt, Greenfield, & Stovall, 2005) to create a care plan is the assumed time and effort required (Tevaarwek et al., 2014). Tevaarwek et al. (2014) suggested the use of the electronic health record (EHR) as an efficient and widely accessible method of documenting a care plan. The average time for creation of a care plan in the EHR was three minutes, and high patient satisfaction resulted (Tevaarwek et al., 2014). An example care plan is provided (see Figure 1).

Implications for Practice and Conclusion

Although prognosis for patients diagnosed with pancreatic cancer is often poor, a significant need remains for survivorship care. Communication between providers is key to holistic management of cancer. Using a simple tool, such as the example care plan from the current article, has the potential to affect detection of side effects and complications of therapy, which could expedite appropriate treatment. Engaging patients and caregivers in an assessment of current symptoms is one way to empower them to take an active role in their care.

References

- American Cancer Society. (2014). *Pancreatic cancer*. Retrieved from <http://www.cancer.org/acs/groups/cid/documents/webcontent/003131-pdf.pdf>
- Broudo, M.W. (2010). Pancreatic cancer: Current practice, future directions. *Radiation Therapist, 19*, 122-148.
- Birken, S.A., Deal, A.M., Mayer, D.K., & Weiner, B.J. (2014). Following through: The consistency of survivorship care plan use in United States cancer programs. *Journal of Cancer Education, 29*, 689-697.
- Campen, C.J., Dragovich, T., & Baker, A.F. (2011). Management strategies in pancreatic cancer. *American Journal of Health-System Pharmacy, 68*, 573-584. doi:10.2146/ajhp100254
- Centers for Disease Control and Prevention. (2010). Leading causes of death. Retrieved from <http://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>
- Eastern Cooperative Oncology Group. (2006). ECOG performance status. Retrieved from http://www.ecog.org/general/perf_stat.html
- Elnahal, S.M., Pronovost, P.J., & Herman, J.M. (2013). More than the sum of its parts: How multidisciplinary cancer care can benefit patients, providers, and health systems. *Journal of the National Comprehensive Cancer Network, 11*, 738-742.
- Hayes, C. (2012). The here and now of pancreatic cancer. *Gastrointestinal Nursing, 9*(10), 28-33.
- Hewitt, M., Greenfield, S., & Stovall, E. (Eds.). (2005). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- MacIntyre, J. (2011). Metastatic pancreatic cancer: What can nurses do? *Clinical Journal of Oncology Nursing, 15*, 424-428.
- Morgan, M.A. (2009). Cancer survivorship: History, quality-of-life issues, and the evolving multidisciplinary approach to implementation of cancer survivorship care plans. *Oncology Nursing Forum, 36*, 429-436. doi:10.1188/09.ONF.429-436
- National Cancer Institute. (2014). Pancreatic cancer. Retrieved from <http://www.cancer.gov/cancertopics/types/pancreatic>
- National Comprehensive Cancer Network. (2014). *Survivorship [v.1.2014]*. Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf
- Pawlik, T.M., Laheru, D., Hruban, R.H., Coleman, J., Wolfgang, C.L., Campbell, K., . . . Herman, J.M. (2008). Evaluating the impact of a single-day multidisciplinary clinic on the management of pancreatic cancer. *Annals of Surgical Oncology, 15*, 2081-2088. doi:10.1245/s10434-008-9929-7
- Robin Yabroff, K., Short, P.F., Machlin, S., Dowling, E., Rozjabek, H., Li, C., . . . Virgo, K.S. (2013). Access to preventive health care for cancer survivors. *American Journal of Preventive Medicine, 45*, 304-312. doi:10.1016/j.amepre.2013.04.021
- Tevaarwerk, A.J., Wisinski, K.B., Buhr, K.A., Njiaju, U.O., Tun, M., Donohue, S., . . . Sesto, M.E. (2014). Leveraging electronic health record systems to create and provide electronic cancer survivorship care plans: A pilot study. *Journal of Oncology Practice, 10*, E150-E159.
- Torgerson, S., & Wiebe, L.A. (2013). Supportive care of the patient with advanced pancreatic cancer. *Oncology, 27*, 183-190.
- Vincent, A., Herman, J., Schulick, R., Hruban, R.H., & Goggins, M. (2011). Pancreatic cancer. *Lancet, 378*, 607-620. doi:10.1016/S0140-6736(10)62307-0
- Wolfgang, C.L., Herman, J.M., Laheru, D.A., Klein, A.P., Erdek, M.A., Fishman, E.K., & Hruban, R.H. (2013). Recent progress in pancreatic cancer. *CA: A Cancer Journal for Clinicians, 63*, 318-348. doi:10.3322/caac.21190