Providing care to patients with pancreatic cancer: A retrospective chart review

by Heather Wilson, Lorna J. Butler, Gloria Repetto, and Jonathan Love

Abstract

Pancreatic cancer may be considered rare, yet in Canada it is the fourth leading cause of death by cancer in the elderly. This study was conducted in a large tertiary centre to determine the symptoms experienced by patients and the response by health professionals in providing supportive care. This paper reports the results of a retrospective review of health records from patients diagnosed with pancreatic cancer (n=99). Results indicate that pain, nausea, vomiting, and anorexia were frequently reported.

There was a lack of consistency in the documentation of nursing care and little evidence of an organized, planned approach for care delivery. The role of the interdisciplinary health care team and its members in managing this devastating disease and its impact on patient quality of life was difficult to ascertain. The development of an integrated approach to the care of patients with pancreatic cancer is presented.

Relative to other types of cancer, pancreatic cancer may be considered rare. However, cancer of the pancreas is the fourth leading cause of deaths by cancer in Canada (NCIC & Health Canada, 1998). Pancreatic cancer is most common in the older population (65-79 years), and a higher incidence is noted in smokers and diabetics. Recent literature also supports the influence of alcohol abuse and high fat diets on the incidence of pancreatic cancer (Greifzu & Dest, 1991; Tempero et al., 1998; Ulander, Grahn, Sundahl, & Jeppsson, 1991).

There remains much debate over the management of pancreatic cancer. Currently, the two most common choices are either pancreaticoduodenectomy, commonly termed Whipples procedure, or non-operative palliation through endoscopic stenting. Given that pancreatic cancer is often diagnosed at a stage when neither surgery nor other treatments such as chemotherapy or radiation will prolong survival time, careful consideration must be given to which treatment is most appropriate for the individual patient. In many cases, attention to relief of symptoms becomes paramount.

Literature review

The poor prognosis associated with pancreatic cancer is often related to difficulties in trying to diagnose the disease. Individuals frequently present with vague complaints, such as anorexia, vomiting, diarrhea, weight loss, and abdominal pain, which can be associated with various illnesses and functional disorders. Lengthy delays in diagnosis may occur as orthopedic or neurosurgical investigations are conducted for complaints of chronic pain syndromes (Frogge, 1987; Holland et al., 1986; Krech & Walsh, 1991; Shakin & Holland, 1988). In addition, radiological testing may not be sensitive enough to detect early stages of the disease (Foltz, 1988; Greifzu & Dest, 1991; Krech & Walsh). Consequently, most pancreatic cancers are diagnosed at an advanced stage when curative resection is unlikely and mortality rates are high (Reber, 1988; Stephens, 1998). In the majority of cases, symptoms related to metastasis beyond the pancreas lead to the diagnosis. Jaundice and pruritus of the extremities are key diagnostic factors. In addition, hepatomegaly and elevated serum levels of alkaline phosphates, bilirubin, and transaminase reflect obstruction of the common bile duct or spread of the cancer to the liver (Horton, 1988; Reber).

Treatment of cancer in the head of the pancreas is usually by surgical resection. Due to local and/or distant metastases, tumours in the body or tail of the pancreas can rarely be resected. When surgery is intended as a cure, a pancreaticoduodenectomy is performed. This involves resecting the distal stomach, common bile duct, gallbladder, duodenum, and pancreas. Given the debilitating effects of the disease, compounded by surgical intervention, patients who undergo pancreatic resection generally have a prolonged recovery. Nursing care of these patients is complex. The goals of post-operative management include monitoring and regulating volume losses, blood glucose, and metabolic abnormalities; providing nutritional support; managing pain; and preventing infection (Spross, Manolatos, & Thorpe, 1988). Although the intent of this surgery is cure, less than 10% of patients survive one year after diagnosis (Burris et al., 1997). Low survival rates raise the question of how a patient's quality of life is factored into the decision-making process for surgery, especially considering its profound effects on one's life.

When the cancer is considered incurable, management of symptoms takes priority and the principles of palliative care are followed. Percutaneous or endoscopically inserted biliary stents are often used to maintain patency of the ductal system and prevent obstruction in order to relieve jaundice and pruritus. Patients with a duodenal obstruction may require a gastro-jejunostomy or duodenal metal stents to allow food to pass (Reber, 1988).

There is little support for providing radiation or chemotherapy because these treatment options potentially add to the number of symptoms experienced. However, the introduction of gemcitabine™, as a first line therapy for patients with advanced pancreatic cancer, holds promise of a decreased morbidity and an increased treatment response (Burris, et al., 1997). Nurses have a key role in providing information and supporting patients' and families' decision-making surrounding treatment options.

A major concern of patients with pancreatic cancer is adequate pain control. Several articles discuss pain management, yet it is unclear if the authors refer to pain related to disease progression or to treatment (Minsky, Hilaris, & Fuks, 1988; Spross et al., 1988). While palliative surgical procedures emphasize significant outcomes for gastrointestinal (GI) symptom management, the effect on pain relief is unknown (Foley, 1988). In order to provide effective management, one needs to define the nature of pain associated with pancreatic cancer. Sources of this pain may include surgery, nerve entrapment, tumour

ABRÉGÉ - SOINS AUX PATIENTS ATTEINTS DE CANCER DU PANCRÉAS : ÉTUDE RÉTROSPECTIVE DES DOSSIERS

On considère parfois que le cancer du pancréas est une maladie rare alors qu'au Canada, il constitue la quatrième cause de décès par cancer chez les personnes âgées. Cette étude a été réalisée dans un grand établissement de soins de santé tertiaires en vue de dégager les symptômes éprouvés par les patients et de déterminer les interventions mises en œuvre par les professionnels de la santé dans le cadre de la prestation de soins de soutien. Cet article présente les résultats d'une étude rétrospective des dossiers médicaux de patients diagnostiqués d'un cancer du pancréas (n=99). Les résultats indiquent que la douleur, la nausée, les vomissements et l'anorexie sont les symptômes les plus souvent rapportés.

La documentation des soins infirmiers manquait d'uniformité, et il n'était guère évident que la prestation des soins reposait sur une approche organisée et planifiée. Il était difficile de cerner avec précision le rôle de l'équipe de santé interdisciplinaire et de ses membres au niveau de la gestion de cette maladie dévastatrice et de son impact sur la qualité de vie des patients. On présente l'élaboration d'une démarche intégrée des soins aux patients atteints de cancer du pancréas.

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compression of nearby structures, biliary obstruction, and inflammation from leakage of pancreatic enzymes outside the ductal system. A comprehensive pain assessment also needs to focus on the quality and quantity of pain, using a pain intensity scale, as well as precipitating and alleviating factors (Held-Warmkessel, Volpe, & Waldman, 1998). Patients who receive adequate pain relief as early as possible can then retain hope that their eventual death will be free from pain, whether at home or in hospital (Foley).

Regardless of treatment intervention, patients with pancreatic cancer frequently experience anorexia, nausea, vomiting, and weight loss. Fat malabsorption and anorexia are significant factors in the development of malnutrition (Held-Warmkessel et al., 1998). These symptoms coupled with fatigue, pruritus, and alteration in bowel habits clearly present many challenges to professional caregivers. Nurses who work in this specialty area are consistently exposed to the devastation experienced by these patients and their families.

Unfortunately, there is little evidence in the nursing literature concerning the care of this group of patients. Quality of life assessment is essentially absent and symptom management is non-specific. While advances in medicine now provide patients and families with a more prolonged and less complicated timeframe, nursing has yet to demonstrate a leadership role in helping families adjust to the threatening experience and find some sense of meaning in what is happening. Clearly, there is a role for nurses to offer strategies that might help patients and family members cope with each event. These strategies may sustain or improve quality of life for patients and maximize the time that patients and families have left together. Moreover, the provision of care to individuals with pancreatic cancer is not discipline-specific, but requires an interdisciplinary approach to ensure optimal symptom management and quality of life. However, in the absence of a well-defined plan of care, approaches for surgical interventions and the provision of community support are inconsistent.

In the Canadian population, individuals with pancreatic cancer may represent a vulnerable societal group for whom health professionals

must be prepared to care, particularly in regards to quality of life issues and palliative care (Health Canada, 1997). At the study site, patients with hepatobiliary diseases are looked after by an interdisciplinary health care team consisting of medical and surgical gastroenterology specialists, nurses, dietitians, psychologists, social workers, and consultants from the palliative care and pain clinic staff. With a focus on early discharge and home care, emphasis is placed on daily nursing assessment of symptom control and care planning. The consultation and efficient involvement of supportive services is coordinated by the nursing staff. Key to this process is the identification of patient and family needs, as well as the coping strategies used in adjusting to changes in their lives related to the cancer. While patient/family education resources have been developed to help provide appropriate information on cancer of the pancreas and the events most likely to occur during hospitalization, little emphasis had been placed on identifying psychosocial issues related to quality of life. The nursing staff realized the limitations imposed by this gap in the literature when trying to plan care given the complexities of this disease. Their concerns raised awareness and promoted discussions on developing an evidence-based approach for their nursing practice. In response to their clinical practice questions, a research team was established.

The purpose of this study was to examine the current practice of care delivery for Nova Scotians diagnosed with pancreatic cancer; specifically, the role of nursing at the Queen Elizabeth II Health Sciences Centre (QEII). A chart review was considered to be the most appropriate method to collect baseline data. The overall aims of the study were to retrospectively assess the documented care needs of patients with pancreatic cancer and their families, as well as the responses of the health care team in meeting those needs. This paper will present the findings describing the symptoms and treatment of patients admitted to the hospital for pancreatic cancer, determining how nurses assessed patient and family needs and then delivered care, and describing the members of the interdisciplinary health care team and their identified roles as documented in the health record.

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Method

A retrospective chart review was conducted to assess the practices of care delivery to patients admitted to the study centre with a diagnosis of cancer of the pancreas. Health records covering the period from 1993-1996 were reviewed. Approval was obtained through the QEII's health records review process.

Procedure

Data obtained from the Nova Scotia Cancer Registry revealed that approximately 541 individuals were diagnosed with cancer of the pancreas between 1990 and 1994 inclusive. Given that the Victoria General was the major referral centre for gastroenterology in Atlantic Canada, it was assumed that most patients would have been admitted to the hospital for medical and/or surgical intervention. At the time the study was initiated, the VG merged with three hospitals to become the QEII Health Sciences Centre. Within the merged centres, it was not known how many different health care teams could have been involved in providing care, how many different nursing units admitted patients pre-operatively, or how many surgical interventions were performed. Therefore, the chart review was confined to only the VG site. Three hundred charts were identified that met the inclusion criteria for patients with an admission diagnosis of pancreatic cancer. Given the complexity of the documents and the charting methods used, the time required to review the records was extensive. Funding did not allow for completion of the total number of charts. Subsequently, the full sample was not realized. Ninety-nine charts were reviewed and comprise the study sample.

Instrumentation

Data were collected from the health records using a form designed specifically for this study. The tool was based on one used in a similar study where the health records of patients who underwent subtotal pancreatectomy for cancer were reviewed (Ulander et al., 1991). Content validity of the tool used in the current study was determined by a panel of five health care professionals with expertise in this clinical speciality. The panel was comprised of three clinically expert nurses, one nurse educator in oncology, and one physician.

A nurse experienced in GI clinical practice and who had completed her baccalaureate in nursing was hired to collect the data from the health records. The data collection instruments were comprised of three main sections: 1) demographic data to describe the study sample, such as personal characteristics of age, marital status, gender, and co-morbidity; 2) the "illness experience" to capture presenting symptoms at the time of diagnosis, surgical intervention, post-operative symptoms, and the role of the health care team in providing symptom management; and 3) the "health care team" section to identify the approach used for care delivery, such as consultations, discharge planning, and hospital re-admissions.

Table One: Surgical intervention (N=99)

Procedure	Number of patients
Diagnostic only:	
Laparotomy	4
Resection:	
- Whipple	9
- Pancreatic resection (distal)	1
- Pancreatectomy	2
Palliation:	
- Gastrojejunostomy	9
- Choledochojunostomy	1
- Jejunostomy	2
- Cholecystojejunostomy	1
- Small bowel bypass	1
- ERCP with stenting	10
- Other	4
No surgical intervention:	55
Total	99

Data analysis

Descriptive statistics were used to describe the documented care needs of patients and family members and the responses of health care professionals to those needs during the initial diagnosis and subsequent treatment. Statistical analysis was facilitated by assigning numerical codes to data; for example, binomial no/yes responses were coded as 0 or 1. SAS statistical programming was employed to conduct the analyses.

Results

Of the 99 charts reviewed, slightly more than half were for female patients (n=53). The average age of all subjects was 69 years. Most patients were married (61%), of Caucasian origin (94%), and lived in central Nova Scotia (67%). For the majority, cancer of the pancreas was reported as the primary site of origin (91%) with the most common location being the pancreas head (66%). Length of survival from the time of diagnosis ranged from one week to 52 months with the majority surviving less than six months.

Diagnostic and surgical intervention

All patients, except four, underwent diagnostic investigation to confirm the extent of disease and/or to facilitate planning of treatment modalities. Of these 95 patients, 73% had two or more diagnostic procedures completed during their initial hospitalization.

Approximately one-third of the patients were treated with surgical intervention or endoscopic stenting (see Table One). While laparotomy was performed in several cases, it was only done to determine operability by confirming the absence of peritoneal and liver metastasis. The most common reason for surgical intervention was to relieve symptoms (see Table One).

Symptoms

At the time of admission to hospital, the majority of patients (n=76) reported experiencing pain, although most were not taking analgesia for pain management. Abdominal pain was the most

Table Two: Symptoms - Pain (N=99)

Location	Number of patients
No Pain	6
Abdominal (Abd)	32
Incisional (In)	14
Low Back (LB)	6
Combination (Abd/In/LB)	34
Other	5
Missing Data	2

Table Three: Symptoms experienced during hospitalization (N=99)

Symptom	Number of patients	Percentage
Nausea and anorexia	22	22%
Nausea and vomiting	18	18%
Nausea alone	18	18%
Nausea, vomiting, and anorexia	15	15%
Anorexia alone	10	10%
Skin:		
Jaundice	54	54%
Pruritus	19	19%
Edema	19	19%
Breakdown	14	14%
Alterations in bowel habits: *		
Constipation	35	40%
Diarrhea	29	33%
* Missing data (n=86)		

prevalent site recorded (n=43). Pain continued to be the most common symptom experienced by these patients while in hospital (n=91), with slightly more than one-third of patients reporting pain in more than one area. The abdomen remained the single most prevalent site (33%), and 15% of patients reported incisional pain (see Table Two). While only 40% of the patients used analgesics prior to hospitalization, 96% received analgesia to control their pain during the initial hospitalization. Other presenting symptoms on admission included jaundice (n=35), diarrhea (n=27), and constipation (n=22).

During hospitalization, 82% of patients experienced one or more GI-related symptoms. Of these, 60% had more than one symptom, the most common being nausea, vomiting, and/or anorexia. The majority of patients also experienced alteration in bowel habits, particularly constipation (40%) and diarrhea (33%) (see Table Three). Documentation of food intake was evident on only 13% of the charts reviewed. Data on muscle loss and loss of subcutaneous fat were recorded on 10% and 13% of charts respectively. Despite the significant number of patients with identified symptoms that could potentially contribute to inadequate nutritional intake, consultation by a dietitian was recorded for only two patients.

Seventy-eight patients reported symptoms affecting the skin. Jaundice was prevalent for more than 50% of patients (n=54), edema (n=19), pruritus (n=19), and skin breakdown (n=14) were also noted (see Table Three).

Documented nursing plan of care

Although pain was the predominant symptom, no standardized assessment tool was evident in the health record to evaluate pain symptoms and characteristics. When comparing the charted notes with the nursing plan of care, using standard nursing diagnoses (Gordon, 1994), the assessment of alteration in comfort was documented for the majority of patients (n=94) while planning, implementation, and evaluation of comfort measures were not consistently recorded (see Table Four).

Ten nursing diagnoses were recorded in the health records: activity intolerance, coping deficit, knowledge deficit, impaired mobility, alteration in nutrition, alteration in comfort, self care deficit, altered sexuality, impaired skin integrity and alteration in elimination. However, documentation of the full nursing process for each of these diagnoses was lacking. Assessment was evident in at least 50% of the charts with the exceptions of coping and knowledge deficits (46% respectively) and sexuality (4%). Only three of the 10 diagnoses had the planning component completed in at least 20% of the charts.

Table Four: Nursing diagnoses (n=99)

Nursing Diagnosis	Assessment	Planning	Implementation	Evaluation
Alteration in comfort	94	32	87	69
Alteration in nutrition	88	26	55	16
Alteration in elimination	82	13	54	36
Self-care deficit	72	4	65	3
Activity intolerance	71	7	44	7
Impaired skin integrity	70	12	59	29
Impaired mobility	67	8	58	8
Coping deficit	46	21	37	29
Knowledge deficit	46	9	44	25
Altered sexuality	4	4	4	4

While the implementation phase of the process was recorded in more than half the charts, few charts had a documented evaluation of the plan of care (see Table Four).

Interdisciplinary team

In addition to nurses and physicians, the interdisciplinary team was comprised of a variety of health team members. Seventy-four patients had a written request for consultation with other health care specialists. Most consults related to further treatment intervention such as radiation therapy (n=45), and supportive care services of physiotherapy (n=17) and/or palliative care (n=7). Information gathered during chart reviews did not clearly depict the role of an interdisciplinary health care team or its members. The only recorded data were related to prescribed recommendations in the referral record.

Discussion

The multiple distressing symptoms, such as pain, nausea, vomiting, anorexia, jaundice, pruritus, and alteration in bowel habits, that these patients experienced, as reported in the chart review, are consistent with the literature depicting clinical presentation of individuals with pancreatic cancer (Greifzu & Dest, 1991; Held-Warmkessel et al., 1998; Ulander et al., 1991). One may infer that a patient's quality of life could be compromised by the number and prevalence of these symptoms, particularly given the short survival time expected from the time of diagnosis. The incidence of these symptoms, from both pancreatic cancer and its treatment, underscores the importance of early recognition and intervention by health care providers to maintain or enhance patients' and families' quality of life.

It has been well-documented that patients with pancreatic cancer present with a variety of pain symptoms that can be divided into a series of acute or chronic pain syndromes. At the time of presentation, the type of pain and its pattern of symptoms are closely related to location of the tumour within the pancreas (Foley, 1988; Held-Warmkessel et al., 1998). Identification of pain as the single most common symptom, both at the time of initial admission and throughout the patient's stay in hospital, supports the need for a comprehensive approach to pain management that emphasizes early intervention and a well-documented plan of care.

While alteration in comfort was recorded in the majority of health records, specific pain symptoms and characteristics were often not captured. Presentation of pain and its underlying etiology may vary amongst individual patients, as well as for patients at diverse stages of their illness. Nurses caring for patients with pancreatic cancer must be knowledgeable in the identification and management of pain symptoms. Use of a standardized pain assessment tool may promote a consistent and systematic approach to pain assessment and documentation of evidence that would support administration of appropriate pain control measures.

Patients with pancreatic cancer are often malnourished (Held-Warmkessel et al., 1998; Ulander et al., 1991). Data from the chart review identified a significant number of patients who presented with symptoms of nausea, vomiting, and anorexia. Yet, a comprehensive approach to nursing management of altered nutrition was not evident in the health record, particularly with respect to care planning and evaluation. As supported by Ottery (1995), these symptoms increase the challenge of maintaining adequate nutrition and invariably affect the patient's quality of life. Nurses have an important role to play in the management of symptoms that affect the patient's nutritional intake. Early detection of potential or actual problems through an adequate nutritional assessment may facilitate the provision of individualized care. Intervention should be targeted towards control of nausea and vomiting through employment of antiemetic agents, regulation of dietary fat consumption, and use of GI stimulants such as metoclopramide or cisapride to manage delayed gastric emptying. Consultation with the dietitian to supplement identified strategies and assist with meal planning could also enhance nutritional care planning (Held-Warmkessel et al.).

The goal of this study was to determine the clinical indicators of quality of life in pancreatic cancer as identified by health

professionals in documenting symptomology and the resulting provision of care. The inclusion of staff from the nursing unit in preparing for and collecting data was motivating for continued learning about pancreatic cancer. The results, while surprising to staff, have led to a heightened awareness of this disease and the limited options for long-term survival. Nurses immediately began to focus on this approach to care planning and documentation from a holistic perspective rather than the traditional completion of tasks.

Recognition of the importance of identifying and using community resources within the home, given the poor prognosis of this disease, was a significant outcome. This led to the coordination of a multidisciplinary team approach with organized patient-centred conferences. A spirit of determination and a willingness to work together evolved, creating a sense of collegiality and respect for each individual's contribution. The results of this chart review were the driving force for examining nursing practice in the care of patients with pancreatic cancer. Continuous improvement in communicating, both written (chart) and oral (team sharing), has been a key outcome.

Limitations

When conducting a retrospective chart review, researchers may be restricted in their ability to obtain information which accurately reflects actual provision of care because only data that have been recorded can be collected and analyzed. Absent and incomplete documentation from nurses and other health care workers regarding symptom control was evident in this study. Information pertaining to the involvement of multidisciplinary team members in the plan of care for pancreatic cancer patients and their families was not captured in the chart review. In addition, data obtained on consultation with various team members simply listed the department/team member consulted. Finally, examination of the consultation process was limited by lack of data to determine if the consult was external or internal.

At the time of the study, there was no consistent use of nursing diagnoses within the nursing division at the study hospital. Although the nursing admission assessment form used a nursing diagnosis format, it was not reflected in the method of charting. Additionally, the system of focused charting used at the time of data collection did not support documentation of the planning component of care. While the nursing plan of care may have been evident in the Nursing Kardex, this document was not a permanent part of the health record at the time of data collection.

Registry data were available for patients residing in the province of Nova Scotia (80% of sample). Yet, because the study hospital serves the Atlantic Canada region, there were no data available for out-of-province patients once discharged from hospital. Therefore, information on confirmation of diagnosis and survival time, if not captured on the inpatient health record, could not be retrieved.

Conclusion

Pancreatic cancer has a poor prognosis with a short survival time. The multisymptomatic nature of the disease reported in the literature was also evident in the current retrospective chart review. While pain was the most predominant symptom, other symptoms such as anorexia, nausea, vomiting, and alteration in bowel habits were also present. Given the short timeframe from diagnosis to death, nurses have a unique opportunity to assist patients and their families to adjust to the devastating experience of pancreatic cancer and find some sense of meaning in what is happening, and to promote quality of life through symptom management. Enhanced communication through identification and documentation of the symptom and treatment experiences of patients with pancreatic cancer provides nurses and other health team members with the necessary foundation to meet the unique needs of the patient and family, given the limited time they have left together.

The findings of this study have increased the nurses' awareness of the gaps in care for patients with pancreatic cancer and their families, particularly with respect to the needs identification and provision of care related to quality of life indicators. The resulting practice change

has led to a significant improvement in communication through both documentation and team sharing. It has also enhanced the nurses' ability to advocate for appropriate symptom management within the interdisciplinary team setting.

This chart review provides the groundwork for further study of quality of life using a prospective approach to examine provision of care based on the experiences of patients with pancreatic cancer and their families. These data could augment the identification of relevant indicators in the development of Canadian practice guidelines for pancreatic cancer.

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