THE EXPERIENCE AND COMMUNICATION OF SYMPTOMS IN ADVANCED PANCREATIC CANCER PATIENTS AND THEIR FAMILIES

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THE EXPERIENCE AND COMMUNICATION OF SYMPTOMS IN ADVANCED PANCREATIC CANCER PATIENTS AND THEIR FAMILIES

Symptom management is the main focus of care for patients living with advanced pancreatic cancer (APC). However, evidence shows that symptom management is far from satisfactory for this population. Poorly managed symptoms have had a profound negative impact on APC patients' and caregivers' life. While communicating symptoms with healthcare providers is the first step to achieve effective symptom management, some studies have revealed the poor quality of symptom discussions among cancer patients, their caregivers, and healthcare providers.

The purpose of this dissertation was to advance the sciences of nursing, symptom management, and patient/caregiver and provider communication in patients with APC. Chapter two, three, and four represented three sub-studies which addressed three specific aims: (1) synthesizing the current evidence regarding the symptom experience of patients with APC, (2) examining recorded healthcare encounters between patients with APC, their caregivers, and healthcare providers to better understand the symptom experiences of patients with APC as told to their healthcare providers, and (3) developing a typology describing patterns and essential elements of real discussions between APC patients/ caregivers and healthcare providers in regards to symptoms. Specifically, chapter two was an integrative review which synthesized sixteen quantitative studies (n=1630 pancreatic cancer patients) and found that pain, fatigue, and appetite loss were primary and intense symptoms experienced by patients with APC. Chapter three was a qualitative descriptive study which used content analysis to examine 37 transcripts of APC patient/caregiver-provider health encounters originally collected for a larger communication study. This study identified ten major symptom groups often described as intense, distressing, and negatively impacting their quality of life. For chapter four, thematic analysis was used to examine 37 transcripts of APC/giver and provider interactions to develop a typology to describe patterns of interactions in regards to symptoms and symptom management. Eight common patient/caregiver-provider interaction patterns regarding symptoms and symptom management were identified. These typologies can be used to enhance patient/caregiver and provider communication programs to promote patient-centered care and improve symptom management in patients with APC. Findings overall will contribute to effective symptom management as it will deepen our understanding of symptom experience and communication processes.

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ABBREVIATIONS

Abbreviations	Terms
APC	Advanced pancreatic cancer
BCOG	Behavioral Cooperative Oncology Group
CMC	Conceptual Model of Communication and Health Outcomes
DPT	Dual Process Theory of Supportive Message Outcomes
mTOUS	Armstrong’s modification of the Theory of Unpleasant Symptoms
SMT	Symptom Management Theory
VOICE	Values and Options in Cancer Care
VPN	Virtual Private Network

CHAPTER ONE

The chapter provides the background and discussion of the research, “The Symptom Experience of Patients with Advanced Pancreatic Cancer: An Integrative Review”, “Symptom Experiences in Patients with Advanced Pancreatic Cancer as Reported During Healthcare Encounters”, and “Patterns of Interactions Among Patients with Advanced Pancreatic Cancer, Their Caregivers, and Healthcare Providers During Symptom Discussions.”

Background and Significance

Pancreatic cancer is one of the most challenging types of cancer because there are no effective prevention strategies, early detection methods, or promising treatments. Pancreatic cancer is the fourth ranked cause of cancer death among adults in the United States with 40,560 estimated deaths for 2015.[1-1] The death rate of pancreatic cancer has increased slowly over the past decade despite the significant improvement in survival rates for most other types of cancer. Scientists predict that by 2030, pancreatic cancer will be the second leading cause of cancer death in the US.1[1-2] The majority of patients are diagnosed with advanced stage disease, and the overall five-year survival rate for most patients with advanced pancreatic cancer (APC) is only 2%.[1-1, 1-3]

Symptoms are self-perceived indicators of change in normal functioning.[1-4] Effective symptom management is imperative for patients with APC due to their limited life expectancy, complicated treatment regimes, rapid physical deterioration, and the debilitating nature of some of the symptoms.[1-1, 1-3] Poorly managed symptoms have been shown to interfere with functioning, health-related quality of life, a good death, and decision-making at the end-of-life in cancer population.[1-4-1-7] Moreover, failure to manage one symptom can exacerbate others.[1-8, 1-9] For example, poorly controlled pain can negatively affect mood and cognitive functioning.[1-10] In addition, poorly managed symptoms can lead to unbearable suffering, which is a contributing factor of patients' wishes for a hastened death.[1-11, 1-12] Poor symptom management can affect caregiver outcomes as well. One study indicated that high symptom burden in advanced cancer patients can predict poor health status in caregivers.[1-13]

Patients with APC often experience distressing physical symptoms that are unrecognized and/or poorly managed by healthcare providers.[1-14-1-18] In addition, these patients experience more psychological distress than persons with other types of cancer.[1-19-1-21] Although some studies have addressed symptoms associated with other terminal cancer populations, such as leukemia, lung, and ovarian cancer,[1-22, 1-23] little is known about the symptom experiences of patients with APC.

Effective symptom management is one of the critical outcomes of effective communication between cancer patients, their caregivers, and their providers. [1-6, 1-24-1-26] Patient-centered communication occurs when providers elicit, show understanding of, or validate the perspectives of patients and caregivers. This communication can improve symptom experiences by encouraging expression of feelings and concerns related to the symptoms, assessing symptoms fully, providing support, and enhancing symptom self-management. [1-6, 1-27, 1-28]

Evidence suggests that there are a number of barriers to effective symptom discussions in healthcare encounters. [1-28-1-31] For example, a qualitative content analysis that explored how cancer patients discuss their pain with their providers revealed that providers asked predominately close-ended questions and frequent interrupted patients. [1-30] In another study of patients with APC, oncologists often finished the sentences of patients who were describing their symptoms, added personal opinions, ignored the patients' descriptions of symptoms, and started new topics. [1-32] Some studies have shown that cancer patients do not always receive symptom management recommendations from healthcare providers. [1-28, 1-33] Patient-related barriers to symptom discussions in cancer populations, such as low motivation for discussing significant symptoms with healthcare providers, have also been identified. [1-28, 1-31, 1-34]

Purpose and Aims

Effective patient-provider communication, therefore, is critical to effective symptom management in patients with APC. More information is need, however, on how patients and caregivers experience symptoms and how symptom experiences in this population are discussed in healthcare encounters. The purpose of this dissertation is to advance the sciences of nursing, symptom management, and patient/caregiver and provider communication in patients with APC. The specific aims of this research are to (1) synthesize current evidence regarding symptom experience of patients with APC, (2) examine recorded healthcare encounters between patients with APC, their caregivers, and healthcare providers to better understand the symptom experiences of patients with APC as told to their healthcare providers, and (3) develop a typology to describe patterns of interactions between patients with APC, their caregivers, and healthcare providers in regards to symptoms and symptom management. This dissertation thus addresses two global research priorities in Cancer and Palliative Care: symptom management and communication. [1-35-1-41]

Guiding Theoretical Frameworks

Several theories inform this dissertation project by providing a foundational understanding of symptom experiences and communication processes such as those that occur between patients with APC, caregivers, and providers. These theories include the Symptom Management Theory (SMT), [1-42] Armstrong's modification of the Theory of Unpleasant Symptoms (mTOUS), [1-4] the Dual Process Theory of Supportive Message

Outcomes (DPT), [1-27] and the Conceptual Model of Communication and Health Outcomes (CMC). [1-6]

The SMT [1-42] and the mTOUS [1-4] indicate that symptom experiences are subjective perceptions, evaluations, and responses to changes in normal functioning. It is a multidimensional concept that includes the following aspects: duration, intensity , distress, and quality and are often related to a several short-term and long-term patient and family outcomes. [1-4, 1-5] These outcomes are morbidity, comorbidity, mortality, physical and cognitive functioning, emotional status, self-care ability, quality of life, and costs. [1-4, 1-42] The mTOUS informed the review and synthesis of the literature presented in Chapter 2.

The DPT[1-27] and CMC[1-6] indicate that (a) communication is carried out not only to exchange information but also to fulfill multiple goals, (b) a number factors can affect communication among patients, families, and healthcare providers such as demographic characteristics, past experiences, or the psychological status of the participants, [1-6, 1-27, 1-43] and (c) the quality of communication is closely linked to patient-centeredness.[6] In particular, the DTP indicates that the quality of a message given by a provider can be low, moderate, or high in person-centeredness. Messages that are low in person-centeredness ignore or criticize patients’ feelings. Messages that are moderate in person-centeredness acknowledge the patients’ emotions but do not allow further discussion or offer help to manage the emotions. Messages that are high in person-centeredness identify the patients’ emotions, encourage expression of the emotions, and respond to these emotions. [1-44]

In this research, therefore, we conceptualize symptoms as the patients' and caregivers' personal and complex responses to changes in the patients' normal functioning. We are especially interested in how patients and caregivers describe symptom experiences from their own perspectives. When exploring interactions in healthcare encounters that focus on symptom experiences, we are particularly attuned to the extent to which these encounters are patient-centered and to factors that influence whether the interactions facilitate or hinder discussion of symptom experiences.

Dissertation Sub-studies

This dissertation is composed of three sub-studies, each of which addresses one of the three aims. Each sub-study is described below.

Sub-study 1

To address Aim 1, an integrative literature review was conducted according to Whittemore and Knafl. [1-45] The purpose of this sub-study was to synthesize current evidence regarding APC patients' symptom experiences.[1-46] The methods and the findings of this sub-study appear in Chapter 2 of this document.

Sub-study 2

To address Aim 2, a qualitative description study as described by Sandelowski was conducted. [1-47] The purpose of this sub-study was to examine recorded healthcare encounters between patients with APC, their caregivers, and healthcare providers to better understand the symptom experience of patients with APC as told to their healthcare providers. The methods and the findings of this sub-study appear in Chapter 3 of this document.

Sub-study 3

To address Aim 3, a thematic analysis as described by Braun and Clarke was conducted. [1-48] The purpose of this sub-study was to develop a typology to describe patterns of interactions between patients with APC, their caregivers, and healthcare providers in regards to symptoms and symptom management. The methods and the findings of this sub-study appear in Chapter 4 of this document.

Because the data for Aims 2 and 3 were drawn from a larger study of a communication intervention that produced verbatim transcripts of healthcare encounters between patients with APC, their caregivers, and their healthcare providers, this study (referred to as the parent study) is discussed below.

Parent Study: The Values and Options in Cancer Care (VOICE)

Purpose

The primary goal of the VOICE study (National Cancer Institute, R01CA140419, Clinical Trials Identifier: NCT01485627, dual-PIs: Ronald Epstein and Richard Kravitz) was to test an intervention designed to facilitate communication and decision-making among oncologists, patients with advanced cancer, and their caregivers. The specific hypotheses of VOICE are that, relative to care-as-usual, the intervention will (1) improve physician-patient-caregiver communication about prognosis and treatment choices, improve the physician-patient relationship, and increase shared understanding of the patient's prognosis; (2) improve patient well-being; and (3) affect health services utilization by both reducing the number of aggressive interventions that may undermine the quality of life in the last weeks of life and increasing the use of guideline concordant palliative care and hospice services. [1-49]

Design

The study was a cluster randomized controlled trial in which oncologists were randomly assigned to an intervention or control condition. Patients of oncologists in the intervention condition were assigned to the intervention group, and patients of oncologists in the control condition were assigned to the control group. Participants were requested to complete questionnaires at several time points (i.e., at study entry, after office visits, 2-4 days after office visits, and every 3 months for up to 3 years or until death) and participate in training (for the intervention arm). Participating patients and their caregivers, when available, were required to provide one audio-recorded office visit with their oncologist before and after the intervention.

The intervention for oncologists is a multifaceted, tailored educational intervention involving standardized patient instructors. Patients and caregivers who were chosen in a randomized manner for the intervention participated in a one-hour coaching session to facilitate prioritizing and discussing questions and concerns. The detailed recruiting process and study methods were described elsewhere. [1-49]

Recruitment procedures

VOICE recruited patients with stage three or four solid tumor cancers, caregivers and their oncologists from multiple oncology practices and cancer centers in the Rochester/Buffalo, NY and Sacramento, CA regions (2013—2015). The inclusion criteria for oncologists included the following: (1) were currently in clinical practice at participating institutions, (2) cared for patients with solid tumors, and (3) did not plan to leave the practice during the next 6 months. Patients were recruited if they were (1) currently a patient of an enrolled oncologist, (2) age 21 years or older, (3) diagnosed with

Stage III or IV solid (non-hematological) cancer, and 4) able to understand spoken English. VOICE excluded patients who anticipated bone marrow transplantation, were diagnosed with leukemia or lymphoma, or were hospitalized or in hospice care at recruitment or for baseline measures. The caregivers were recruited if they were (1) caregivers of a patient currently enrolled in the study, (2) age 21 years or older, and (3) able to understand spoken English. VOICE excluded caregivers who supported the patient primarily through a professional role (e.g., clergy). Ethical approval was obtained from the IRBs of the five affiliated institutions where the study was being conducted. All participants (i.e., patients, caregivers, and oncologists) completed written informed consent documents. A total of 383 patients and 276 caregivers participated in the VOICE. Table 1-1 shows the demographic data of all patients who participated in the parent study (VOICE). The transcripts of the audio-recorded office visits from the VOICE study recorded before the intervention were used in this dissertation research.

For the current research, the transcripts of encounters that involved patients with APC were stored in the secure space at Purdue University and were accessed remotely through Virtual Private Network (VPN) or through Purdue campus network with assigned username and password. Most encounters contained three participants: a healthcare provider, a patient, and a caregiver; 117 participants contributed to 37 transcripts. Among the participating caregivers (n=34), 38.24% were wives, 23.53% were husbands, and 14.71% were daughters. The majority of the healthcare providers were male (n=35, 76.09%). Table 1-2 shows the demographic characteristics of the APC patients whose data was used for this research.

Institutional Review and Approval

Prior to beginning this research, the Indiana University Human Subjects Office confirmed the study was an exempt study as private, identifiable information was not accessible and only de-identified transcripts from the VOICE study were provided.

Trustworthiness of the Dissertation Research

To ensure the quality of research, four standards outlined by Miles and colleagues (2013) served as an evaluative framework. The standards are confirmability, reliability, credibility, and transferability.

Confirmability is the extent to which the findings of the research studies that comprised the dissertation were neutral, that is free of researcher bias, and thus can be confirmed by others. The strategies that were used to ensure confirmability include the following: 1) The study processes, especially the analysis plans, were explicitly described and documented, and 2) The dissertation chair and select dissertation committee members monitored the analytic processes and confirmed the findings presented in each sub-study by reviewing all the existing literature (sub-study 1) and transcript data (sub-study 2 and 3). Many of the analytic and methodological decisions were made by group discussion and consensus.

Reliability is whether the study processes remains consistent and stable over time and across researchers. Reliability is based on whether the researcher has taken care to ensure the quality and integrity of the research process. The strategies that were used to ensure reliability for each component were as follows: (1) Clear study aims were established and the study designs were explicit and consistent with each aim, and (2) The researcher’s dissertation committee chair, Dr. Von Ah, and other select dissertation committee members ensured that all study procedures as outlined in this proposal were closely followed.

Credibility is the “truth value” of the findings – that is whether the study findings are authentic and thus make sense to people we study and to readers. To ensure credibility, we obtained feedback on all codes and categories as they emerged from members of the Behavioral Cooperative Oncology Group (BCOG) and dissertation committee members. BCOG members include interdisciplinary PhD students and post-doctoral fellows whose research interest is related to behavioral oncology. BCOG meets regularly to discuss research-related issues.

Transferability is whether the study results can be generalized or transferred to other contexts, populations, or settings. [1-50] Transferability was ensured in this study through a full description of the sample from the parent study (Sub-study 2 and 3) so that readers can determine the extent to which the findings can apply to their own practices.

Table 1-1.
Demographic Characteristics of the Participated Patients of the VOICE Study

	n	% (mean)
All	383	100
Age	382	63.5
Race		
Non-white	41	10.70
White	342	89.30
Site		
UC Davis Cancer Center	136	35.51
University of Rochester Medical Center	247	64.49
Education		
High school or less	110	28.72
Some college or more	273	71.28
Gender		
Male	172	44.91
Female	211	55.09
Income		
Missing	45	11.75
20,000 or less	71	18.54
20,001-50,000	109	28.46
50,001-100,000	111	28.98
Over 100,000	47	12.27
Marital status		
Missing	2	0.52
Committed/ married	250	65.27
Divorced/ separated	69	18.02
Never married	26	6.79
Widowed	36	9.40
Insurance		
Private	151	39.43
Medicare	198	51.70
Medicaid/medical	29	7.57
Other	5	1.31
Religion		
Christianity	274	71.54
Other	35	9.14
No religion	74	19.32
Have consented caregiver		
No	107	27.94
Yes	276	72.06

Table 1-2.

Demographic Characteristics of the Participated Advanced Pancreatic Patients of the Current Study

	n	%
Participated patients	37	100
Gender		
Female	21	56.76
Male	16	43.24
Participated Caregivers	34	91.89
Caregiver Roles		
Husband	8	23.53*
Wife	13	38.24*
Mother	1	2.94*
Daughter	5	14.71*
Son	1	2.94*
Brother	1	2.94*
Sister	2	5.88*
Friends	3	8.82*
Participated Healthcare Providers	46	100**
Oncologist	37	80.43**
Nurse	9	19.57**
Provider's Gender		
Female	11	23.91**
Male	35	76.09**

Note. * Among all participated caregivers for advanced pancreatic cancer patients (n=34)

** Among all participated healthcare providers

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CHAPTER TWO

This chapter describes sub-study 1 which focused on the state of the science of the symptom experience of patients with APC (dissertation aim 1). This sub-study serves as a call to action for further research, especially qualitative study, to understand the symptom experience of patients with APC.

The Symptom Experience of Patients with Advanced Pancreatic Cancer: An Integrative Review[2-1]

Pancreatic cancer is one of the most challenging types of cancer because there are no effective prevention or early detection methods and treatment options are limited. Pancreatic cancer ranks fourth as a cause of cancer deaths, with over 40,500 estimated deaths for 2015 in the United States.[2-2] By 2030, scientists predict that pancreatic cancer will be the second leading cause of cancer death. [2-3] Despite significant improvement in survival rates for many types of cancer, the death rate for pancreatic cancer has slowly increased over the past decade. In fact, the overall five-year survival rate for patients in the advanced stage is approximately only 2%.[2-2, 2-4]

The complexity of the disease and treatment and the rapid physical deterioration pose special challenges to symptom management for patients with advanced pancreatic cancer (APC). Symptoms, which are the "perceived indicators of change in normal functioning as experienced by patients," [2-5(pp68)] may be both complex and severe and significantly impact health related quality of life (HRQOL). For patients with APC and their caregivers, symptom management is the primary goal of care. Yet, though some studies have begun to focus on special symptoms or symptom clusters among different critically ill cancer populations, such as leukemia and lung and ovarian cancer, [2-6-2-8] little is known about the symptom experience of patients living with APC. Emphasis has been placed on developing or evaluating treatment methods rather than symptom management.

There is a lack of comprehensive and systematic approaches to understanding symptoms and their impact in patients with APC. This knowledge gap not only contributes to poor symptom management but also ignores how symptoms interfere with patients' survival duration, HRQOL, psychological health, communication, decision making, and preparing for death.[2-5, 2-9] Furthermore, because of the quick disease progression and terminal stage, APC is an ideal prototype to understand symptom changes and care needs in patients who face rapid transition from healthy status to terminal illness.[2-10, 2-11] Therefore, the purpose of this integrative review was to synthesize current evidence regarding APC patients' symptom experiences. Findings from this review will inform future research directions and help health care providers design comfort measures that support patients as they manage and cope with symptoms.

Methods

This integrative review was designed to fully examine the symptoms experienced by patients with APC and used the methodological strategies proposed by Whittemore and Knafl (2005).[2-12] An integrative review was selected because it allowed us to include heterogeneous resources such as different research methods and varying data collection instruments. The steps of the review included 1) problem identification, 2) literature search, 3) data evaluation, 4) data analysis, and 5) presentation of findings.

Literature Search

Literature describing the symptom experience of patients with APC was identified by searching in four databases: Pubmed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, and PsychINFO. We used two medical subject heading searches to find citations in Pubmed: 1) "pancreatic neoplasms" AND "symptom assessment" OR quality of life" and 2) "pancreatic neoplasms," "signs and symptoms," AND "terminal care." The CINAHL headings of "pancreatic neoplasms" AND "symptoms" OR "quality of life" were used to search in the CINAHL, and the Emtree terms of “pancreas cancer,” “terminally ill patients,” AND “symptoms” OR “quality of life” were used to search in Embase. Emtree terms are hierarchically structured terminologies which are used to index the Embase content. For PsychINFO, subject terms of "neoplasms," "pancreas," AND "symptoms” OR “quality of life" were used. In addition to subject terms, we also used key words (i.e., “pancreatic cancer” AND “stage three” OR “stage four” OR terminal OR palliative) AND (symptoms OR signs OR “quality of life”)) to search aforementioned databases. Search limitations were English language, human sample, and year published (2005-2015) since treatment protocols for APC advance quickly. Each journal article’s reference list was also carefully searched by hand to identify additional pertinent articles. The search results were imported into EndNote X7.5 and duplicates were removed. We then reviewed the titles, abstracts, and full text of the articles based on the inclusion and exclusion criteria to determine their eligibility.

Inclusion and exclusion criteria. Based on the theoretical definition of symptom experience in Armstrong’s concept analysis and Lenz’s Theory of Unpleasant Symptoms, only the patient can report on the symptom experience, including its four dimensions: intensity, timing, quality, and distress. [2-5, 2-13] Therefore, manuscripts included in this review include quantitative, qualitative, and mixed-methods studies focusing on physical or psychological symptoms experienced and reported by patients with APC. APC patients were defined as patients diagnosed with locally advanced or distant pancreatic cancer that was not eligible for curative surgery at diagnosis. We also included studies with heterogeneous cancer patient populations only if the results for those with APC were analyzed separately.

We excluded manuscripts that: (1) did not report on empirical studies, including opinions, case reports, or editorials; (2) were review articles; (3) did not include patient “self-report” of symptoms; or (4) only addressed symptoms related to a specific drug or procedure because the foci of these articles were on drug toxicity or safety/effectiveness of the procedure versus overall symptom experiences. Moreover, studies focused only on specific drug- or procedure-related symptoms often set inclusion criteria of particular symptom intensity (e.g., patients with moderate pain).

Data Extraction

We used an author-developed data coding sheet to conduct the two steps of data extraction. First, we extracted information regarding authors, year of publication, setting characteristics, participant characteristics, and study design. Second, we extracted information with regard to symptom-related variables based on the aforementioned concept analysis and theoretical framework. Third, the symptom-related variables, including type of symptom, measurement instruments, symptom profile (symptom intensity, timing, quality, and distress), and associated factors were identified. The four dimensions of symptom profile were defined based on the Theory of Unpleasant Symptoms. [2-5] Specifically, symptom quality is related to characteristics of symptoms (e.g., “burning” pain). Symptom intensity quantifies the degree, strength, or severity of symptoms. Timing is related to the occurring time, duration, and frequency. The distress dimension refers to the affective aspect or meaning of symptoms. [2-5] After reading the articles, two of the authors (C. T. & D. V.) highlighted relevant information and organized information using the coding sheet. We further created several tables to contrast and compare variables. Tables are presented along with findings in the next paragraph.

Findings

Nine hundred and sixteen articles were initially identified. After removing duplicates (*n*=90), the remaining 826 articles were screened by titles, which resulted in a total of 337 articles remaining. After screening the 337 abstracts using the established criteria, 293 articles were excluded. Among the 293 articles, 44% (*n*=128) did not report results specific to an APC population; 36 % (*n*=106) were non-empirical, non-peer-reviewed, or review articles; 16% (*n*=47) did not include patient-reported symptoms; and 4% (*n*=12) only addressed symptoms related to a specific drug or procedure. Among the 44 articles that were retained for full-text review, 29 were excluded because they (1) did not include patient-reported symptoms (*n*=11), (2) only addressed symptoms related to a specific drug or procedure (*n*=11), (3) did not report results specific to an APC population (*n*=6); and/or (4) were not written in English (*n*=1). A hand search of each manuscript's reference list resulted in adding one more article. Thus, a total of 16 studies was included in the analysis (Figure 2-1).

All 16 studies were quantitative, with five descriptive studies, [2-14-2-18] four correlational studies, [2-19-2-22] and seven quasi-experimental studies. [2-23-2-29] Six of the 16 studies (37.5%) explored overall symptom experiences or the relationship among symptoms in patients with APC, [2-16, 2-18-2-22] and two studies (12.5%) compared symptom experiences across different pancreatic cancer stages. [2-14, 2-17] Five studies (31.25%) focused on pain or pain management strategies for patients with APC, [2-15, 2-23, 2-24, 2-28, 2-29] and the remaining three studies (18.75%) focused on interventions other than pain management.[2-25-2-27] Only 2 of the 16 studies explicitly described a guiding theory or framework. The theoretical frameworks utilized were systematic inflammation[2-18] and descriptions of nociceptive and neuropathic pain.[2-15] The number of study participants ranged from 20 to 654, and the APC patients' medium survival duration for those articles that reported on this variable (*n*=8) was about 6.36 months (range from 3.5 to 8.9 months). About half (*n*=8) of the studies were conducted in Europe[2-16, 2-18, 2-19, 2-22-2-25, 2-27] and the other half in North America (*n*=7).[2-14, 2-15, 2-17, 2-20, 2-21, 2-26, 2-28] One study was conducted in Asia.[2-29] Table 2-1 displays study aims, designs, population, and symptom-related results. From our review, we organized the studies by symptom types and instruments, symptoms identified, symptom profiles, and factors associated with symptoms.

Instruments

All studies used instruments to evaluate pre-determined symptoms. The 9 instruments used in the 16 studies were in two categories: one focused on evaluating cancer patients' multiple symptoms and HRQOL and the other focused solely on pain. Six instruments that focus on multiple symptoms are the European Organization for Research and Treatment of Cancer (EORCT QLQ-C30) with or without the pancreatic special module (EORCT QLQ-PAN26), the Edmonton Symptom Assessment Scale (ESAS), the European Quality of Life-5 Dimensions (EQ-5D), the Functional Assessment of Cancer Therapy general module (FACT-G) with or without the hepatobiliary module (FACT-HEP), the Linear Analog Scale Assessment (LASA), and the M.D. Anderson Symptom Inventory (MDASI). Table 2-2 displays the symptom inventory captured by these six instruments. Three instruments focused solely on pain are the McGill Melzack Pain Questionnaire, [2-15] the Brief Pain Inventory (BPI), [2-23] and a single item for rating pain intensity and frequency. [2-25] Overall, the EORTC QLQ-C30 and/or EORTC QLQ-PAN26 were the most frequently used measurement tools (*n*=8), [2-14, 2-16, 2-18, 2-19, 2-21, 2-24, 2-27, 2-28] followed by the FACT-G (*n*=2). [2-17, 2-23] Though investigators used a variety of different instruments to measure symptoms, some symptoms are included in instruments more often than others. Specifically, almost all symptom evaluation instruments measured pain and depression symptoms. However, taste change, numbness, and most psychological symptoms were addressed by only one or two instruments.

Symptoms Identified

All studies identified physical symptoms, and nine of the 16 (56.25%) studies[2-14, 2-16, 2-18-2-20, 2-22-2-24, 2-26] also covered psychological symptoms. Table 2-3 shows authors, the symptoms reviewed, and measurement instruments. Importantly, Table 2-3 also displays the problematic symptoms identified by each study and the corresponding operational definitions of problematic symptoms. The physical symptoms identified in the APC samples were pain, fatigue/lack of energy, loss of appetite, dry mouth, taste change, digestive problems (e.g., nausea, vomiting, altered bowel habits, indigestion, and flatulence), respiratory problems (e.g., dyspnea), and poor sleep. The psychological symptoms were related to sense of well-being, anxiety, depression/sadness, emotional distress/mood disturbance, life enjoyment, and fear. Congruent with our previous observation that all instruments measured pain, pain was the most prevalent symptom discussed in all studies, followed by fatigue (*n*=11, 68.75%), digestive symptoms (*n*=9, 56.25%), and loss of appetite (*n*=7, 43.75%). However, although depression was also included in most instruments used, it was only discussed in six (37.5%) of the studies.

Symptom Profile: Intensity, Timing, Quality, and Distress

In this section, we report APC patients' symptom profiles using the Theory of Unpleasant Symptoms' four dimensions: intensity, timing, quality, and distress. The majority of the studies found that patients with APC had substantial physical and psychological symptoms, especially as related to the intensity dimension.[2-14, 2-16-2-29] Compared to the healthy population and early stage pancreatic cancer population, patients with APC reported more total symptoms and more intense symptoms such as fatigue, appetite loss, pain, digestive symptoms (e.g., indigestion), anxiety, and depression.[2-14, 2-16, 2-17, 2-26] Although the researchers used various instruments with different operational definitions to determine the level of intensity of symptoms, they reported that a considerable number (more than 25%) of patients experienced moderate to severe intensity of symptoms that included fatigue,[2-16, 2-19-2-21, 2-27-2-29] loss of appetite,[2-16, 2-19-2-21, 2-27-2-29] pain,[2-14, 2-16, 2-20, 2-21, 2-25-2-28] insomnia,[2-21, 2-27-2-29] digestive symptoms,[2-14, 2-27-2-29] impaired sense of well-being,[2-16, 2-19] anxiety and depression,[2-26] and fear.[2-14] Fatigue, loss of appetite, and pain were the top three severe symptoms reported.

Eleven studies explored fatigue, and most of these reported patients' average fatigue intensity was moderate to severe.[2-16, 2-19-2-21, 2-27-2-29,] In those articles that provided more specific information, 19% to 63% patients experienced moderate to severe fatigue.[2-16, 2-18-2-20] Similarly, studies examining loss of appetite (*n*=7) reported the average intensity of appetite loss was moderate to severe,[2-16, 2-19-2-21, 2-27-2-29] with about 24% to 63% of patients in those articles giving that information having loss of appetite that was moderate to severe. [2-16, 2-19, 2-20] With regard to pain, patients experienced moderate to severe pain on average regardless of treatment types or disease progression. [2-14, 2-16, 2-21, 2-27] Specifically, 15%-43% of patients with APC reported moderate to severe pain. [2-18-2-20, 2-25] Symptom intensity changed along with treatment and disease progress. Though pain[2-21, 2-28, 2-29] and insomnia[2-21, 2-28, 2-29] improved significantly after treatments (e.g., celiac plexus block surgery), the intensity of several physical symptoms including fatigue, [2-29] digestive symptoms, [2-16, 2-19, 2-27, 2-29] dyspnea[2-16], and dry mouth[2-16] worsened with general care, palliative resection, or celiac plexus block surgery. For loss of appetite, some studies found a significant improvement after celiac plexus block surgery; [2-28, 2-29] and other studies demonstrated that the symptom got worse with general care and palliative bypass surgery. [2-21, 2-27]

Among the studies reporting psychological symptoms (*n*=9), the focus was on sense of well-being, [2-16, 2-19, 2-24] depression, [2-16, 2-18-2-20, 2-23, 2-26] and anxiety. [2-16, 2-19, 2-30] Two studies found that patients with APC experienced moderate to severe impairment in their sense of well-being, which worsened as the disease progressed. [2-16, 2-19] Studies presented contradictory findings regarding depression. Some showed that most patients experienced mild depression, with mean intensity scores of 2 to 3 out of 10, [2-16, 2-20] whereas others showed that about 40% of patients experienced moderate to severe depression. [2-18, 2-19] Similarly, Bye and colleagues (2013) found that 37-44% patients experienced moderate to severe intensity of anxiety, although the mean intensity score for anxiety reported by Labori et al. (2006) was at a mild level. Regardless of the intensity level, Romanus et al. (2012) reported that more than half of the patients experienced anxiety and depression. When the disease progressed, the intensity of anxiety and depression stayed the same or slightly increased. [2-16, 2-19] Most studies used EORTC QLQ-C30 to measure anxiety and depression. [2-16, 2-18, 2-19]

Three studies examined the timing dimension of the symptoms, including frequencies[2-25] and possible coexisting symptoms or symptom clusters. [2-18, 2-20] Muller et al. (2008) reported that 51% of the patients with APC had daily pain. For the coexisting symptoms, Reyes-Gibby et al. (2007) reported all possible symptoms, but Laird and colleagues (2011) focused on the common symptom cluster of pain, fatigue, and depression in cancer patients. These two studies found that about 24% to 51% of the patients had two or more coexisting symptoms with moderate to severe levels of intensity. The proportion of patients with such symptoms tended to increase temporarily during chemoradiation. [2-20] Specifically, researchers identified two possible symptom clusters. Laird et al. reported more than double the number of patients who would have been expected to have had the symptom combination of pain, fatigue, and depression if the symptoms were to coexist by chance. Reyes-Gibby et al. (2007) reported a strong relationship between fatigue and loss of appetite. Only one study explored how patients described their symptom quality verbally. [2-15] With a very small sample size, Dobratz (2008) could not distinguish pain patterns (e.g., nociceptive vs. neuropathic pain) based on APC patients’ word choices. No study explored the distress dimension of the symptoms.

Factors Associated with Symptoms

A number of factors were noted to play into APC patients’ symptom experiences. Researchers found that fatigue, loss of appetite, pain, and mood were significantly associated with other factors such as comorbidity, mortality, function or performance level, energy intake, psychological status, HRQOL, social relationships, and survival duration. Specifically, fatigue was negatively associated with energy intake and predicted the interference levels of walking, activity, work, enjoyment of life, and survival. [2-19, 2-20, 2-22] Loss of appetite was not only linked to physical function such as energy intake, walking, and activity, but it also predicted psychological function including mood and enjoyment of life. [2-19, 2-20] Pain was negatively related to performance, energy intake, and relationships with other people. [2-19, 2-20, 2-22, 2-23] One study further indicated that pain intensity can predict survival in patients receiving chemotherapy. In this study, researchers also found that poor performance was associated with impaired mood. [2-22] Low energy intake and complex comorbid medical conditions were linked to higher overall symptom intensity. [2-19, 2-20]

Discussion

The purpose of this review was to synthesize current evidence regarding APC patients' symptom experiences. Based on the 16 reviewed studies, all using a quantitative approach with a pre-determined symptom inventory, our main findings were that patients with APC experienced multiple intense physical symptoms, especially fatigue, loss of appetite, and pain. With limited and inconsistent study results, APC patients' experiences regarding psychological symptoms remains unclear. Similarly, evidence of coexisting symptoms or symptom clusters in the APC population is limited. However, current evidence suggests that coexisting symptoms exist. Although there is no qualitative study met our inclusion criteria, qualitative evidence supported one of our main findings: patients with APC incur a number of complex symptoms that can become debilitating. Qualitative studies exploring terminal pancreatic cancer patients' concerns showed that patients and their caregivers experienced several symptoms and expressed their great concerns about both physical and psychological symptoms.[2-31, 2-32] The following paragraphs further discuss findings in depth with several identified knowledge gaps.

First, the use of various symptom measurement instruments makes it difficult to compare identified symptoms and symptom intensity across studies. Instrument variation is especially problematic when interpreting psychological symptoms because every instrument uses different terms and definitions in relation to psychological symptoms (e.g., depression and sadness). Instruments such as LASA measure psychological symptoms using one general term (i.e., mood) to capture patients' experience with regard to depression, anxiety, and stress. Furthermore, all reviewed studies only focused on intensity dimension of predetermined symptoms because of forced-choice instruments and might ignore other symptoms and other symptom dimensions such as quality and distress. Another problem with regard to the instrument is that using the instruments designed to measure HRQOL to evaluate symptoms, as most of our reviewed articles did, causes difficulties in understanding and managing nutrition-related symptoms.[2-33]

Second, although our results show that fatigue, loss of appetite, and pain were prevalent and intense physical symptoms reported by the patients across studies, these symptoms received disproportionate attention. It is not surprising that pain has been the major focus of studies since pancreatic cancer is widely known to be one of the most painful malignancies.[2-34] All reviewed studies addressed pain and about half of them focused on pain management strategies. In contrast, only half or fewer of the studies mentioned other problematic physical symptoms (e.g., fatigue or loss of appetite) and their symptom management strategies. Our review found that fatigue is a prominent and severe problem in the APC population, which corresponds to existing assumptions in all cancer population. [2-35] On the other hand, there is a growing recognition that loss of appetite is one of the most distressing symptoms for APC and their caregivers, but is often overlooked by health care professionals. [2-36-2-38] Although the etiology of loss of appetite is multifactorial and not fully understood, the experience and management of loss of appetite can be particularly complicated for patients with APC because it may be associated not only with treatment and physical deterioration but also with reduced pancreatic function (e.g., pancreatic exocrine insufficiency) and depression, [2-19, 2-38] which is a prevalent symptom in this context. [2-39] The disproportion emphasis of physical symptoms is not only obvious in research but also observable in the clinical practice. Two articles which reported the most significant problems faced by health care providers when caring for patients with APC only discussed pain and anorexia-cachexia. [2-40, 2-41] Other studies showed that while pain management has been noted as the most frequent intervention provided in the hospice consultation for patients with APC, nutrition related evaluation and intervention was documented in less than 15% of the charts. [2-42, 2-43] This ignorance of non-pain symptoms prohibits health care providers from understanding APC patients' symptom profile fully and addressing their needs. A qualitative study reported that pancreatic cancer patients expressed their lack of knowledge, confidence, resource access, and effective communication with health care providers when managing their digestive symptoms. [2-33] Our limited understanding of these problematic symptoms may also partly explain why there are still no effective symptom management strategies for the majority of the symptoms, although APC patients experienced these intense symptoms until death. For example, whereas general treatments (e.g., chemotherapy) and pain management surgeries (e.g., nerve block) improved pain and insomnia, fatigue and digestive symptoms did not change or even worsened. Studies pointed out that the severe symptoms continuously contribute to APC patients' poor functional status and HRQOL with nutrition and digestion symptoms and fatigue being the most significant symptoms affecting HRQOL. [2-33, 2-42, 2-44]

Third, psychological symptoms also have received insufficient attention. Only about half of the studies addressed psychological symptoms, and there was little in-depth exploration or discussion. Our findings showed different symptom profiles of psychological symptoms and, because of the limited number of studies looking at these symptoms, cannot either support nor reject the mounting evidence of strikingly high psychological distress rates in pancreatic cancer population compared to other types of cancer. [2-39, 2-45, 2-46] For example, although two reviewed studies[2-18, 2-19] found that depression was a severe problem, with approximately 33-50% of the pancreatic cancer patients experiencing depression, [2-39] other researchers[2-16, 2-20] concluded that depression is mild in APC population. These different results may be because of different measurement methods (e.g., mean symptom score vs. the percent of patients with a high symptom score). However, our results do support that psychological distress is elevated when disease progresses over time. [2-47]

Despite the insufficient evidence, qualitative evidence suggested that psychological distress bothers APC patients and their caregivers. Researchers analyzing the types of questions asked by terminal pancreatic cancer patients and their caregivers online indicated that 11-23% of the questions were related to psychological concerns. [2-31, 2-48] Interestingly, while maintaining hope is one of the main themes identified with regard to pancreatic cancer patients' experience,[2-49] only one instrument was used by our sample studies that evaluates hope. None of our sample studies addressed hope in their result or discussion. Although the evidence is not enough to determine the possible cause of psychological symptoms in pancreatic cancer,[2-50, 2-51] it is clear that there is a complicated relationship among patients' physical symptoms, physical symptoms, and health related outcomes. A qualitative study demonstrated that nearly all patients expressed feelings of anger, frustration, and powerless related to the lack of knowledge of symptoms, unfamiliarity of symptom management strategies, and poor symptom control.[2-33] Researchers suggested that the psychological distress is significantly related to poor QOL, fatigue, pain, and loss of appetite in pancreatic cancer population.[2-45]

Fourth, with only three studies exploring pain frequencies and co-existing symptoms, we know little about the timing dimension of the symptoms. Although our findings suggest that symptom clusters may exist, more evidence is needed to determine if there is any unique symptom cluster that is associated with APC. Lastly, we have almost no clues regarding the quality and distress dimension of the symptoms since only one article discussed pain quality and no study explored symptom distress.

Conclusion

To our knowledge, this is the first integrative review to explore symptom experiences of patients living with APC. By synthesizing the important evidence and highlighting the knowledge gaps, this review has important implications for both clinical and research practice. For clinical practice, the review findings help to target problems for improved symptom management in APC patients. Furthermore, we have identified pressing needs to raise awareness of and design interventions for a number of poorly managed and severe symptoms. For future research, given that quantitative methodology has been the predominant approach to examine symptom experience of patients with APC to date, qualitative studies are needed to explore the multiple dimensions of symptoms. For both researchers and clinicians, it is imperative to focus on psychological symptoms, which are still underexplored yet were the main concerns mentioned by patients and caregivers during patient-health care provider discussions.[2-48] Studying psychological symptoms will facilitate a deeper understanding of the high psychological distress rate and the causes so that interventions to alleviate this distress can be developed.

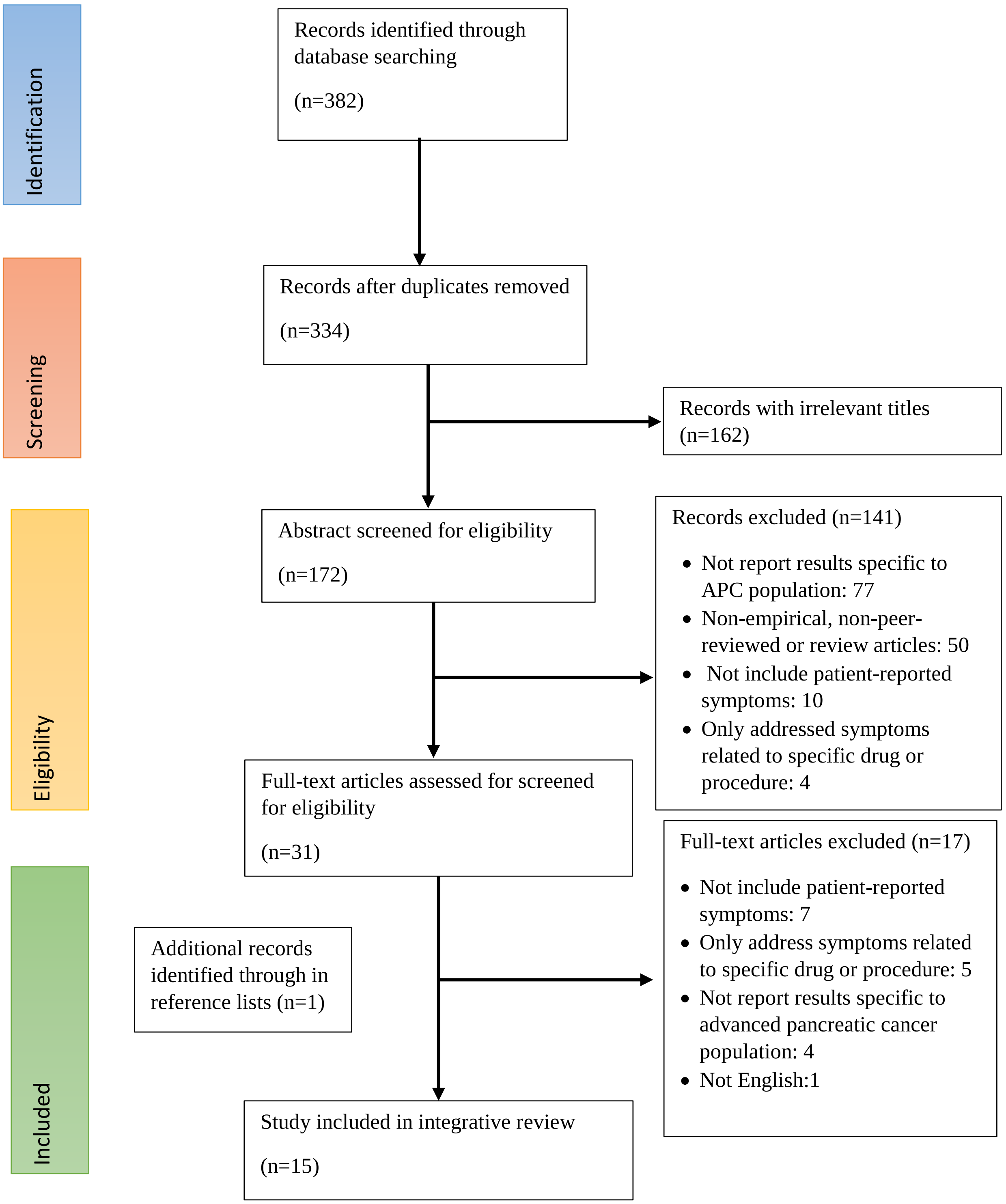

Figure 2-1. PRISMA Diagram of Search Results and Screening Process

Table 2-1. Summary of the Reviewed Studies

First author (year of publish)	Study aim	Study design	Population (n=number of study participants)	Symptom related results [measurement tool]
Allen (2011)	To assess the efficacy of laparoscopic celiac plexus block.	Quantitative; quasi-experimental study	Unresectable pancreatic malignancy with significant pain	**Symptom intensity:** a) Baseline: Mean pain score: 7.8/10 [BPI] and 65.8/100 [EORTC QLQ-C30]. b) Follow-up: pain, insomnia, and appetite loss improved significantly 4 weeks after procedure [EORTC QLQ-C30].
Bye (2012)	To assess energy intake, weight loss and symptoms during the disease course and investigate associations between symptoms and energy intake.	Quantitative, descriptive correlational study	APC (n=39)	**Symptom intensity:** a) Baseline: 37% to 63% patients had moderate to severe intensity of almost all symptoms [ESAS]. Flatulence, oral dryness and indigestion were the most frequent symptoms reported [QLQ-PAN26]. b) Follow-up: minor changes from baseline [ESAS & QLQ-PAN26] **Associating factors:** c) The correlations between energy intake and symptoms become stronger when disease progress: At 2 month follow-up, there is strong negative correlation between energy intake, appetite loss, oral dryness and fatigue. At 3 month follow-up, there is a strong negative correlation between energy intake and appetite loss, pain, dyspnea and flatulence.
Braun (2013)	To examine if baseline QoL and QoL changes from baseline until 3 months after treatment could predict survival in patients with stage IV pancreatic cancer.	Quantitative; descriptive correlational study	Stage IV pancreatic cancer (n=186)	**Symptom intensity:** a) Baseline: In average, patients experienced fatigue (41.8/100), pain (37.6/100), insomnia (36.6/100), and appetite loss (33.3/100) at moderate level [EORTC QLQ-C30]. b) Follow-up: fatigue and appetite loss worsen; pain and insomnia improved 3 months after treatment. **Associating factors:** c) Physical function, social function, fatigue, pain, dyspnea, and global health were predictive of survival.
Crippa (2008)	Evaluate the QoL and survival in patients with different stages of pancreatic cancer	Quantitative; descriptive longitudinal study	Pancreatic cancer (n=92; n of APC: 64)	**Symptom intensity:** APC patients tended to report more abdominal pain than patients had localized pancreatic cancer

Dobratz (2009)	To determine if nociceptive/ neuropathic pain could be identified by word selections	Quantitative; descriptive study	Advanced cancer patients received home-based hospice services (n=76; n of APC: 4)	**Symptom quality:** APC patients showed no distinct pain pattern (nociceptive or neuropathic) in their word choices while colon and liver cancer selected words that described 2 types of nociceptive (visceral, somatic) pain and prostate cancer patients noted somatic pain.
Gao (2014)	To evaluate the effectiveness of standard pain medication with or without NCPB	Quantitative; quasi-experimental study	Unreseactable pancreatic cancer with pain	**Symptom intensity:** a) Baseline: in average, patients experienced fatigue and constipation at moderate level; pain, insomnia, and appetite loss at severe level [EORTC QLQ-C30]. b) Follow-up: pain, appetite loss, and insomnia improved significantly 3 month post-therapy.
Labori (2006)	To describe prospectively the prevalence and severity of disease-related symptoms, QoL and need for palliative care in patients with APC	Quantitative, descriptive longitudinal study	APC (n=51)	**Symptom intensity:** a) Baseline: fatigue and loss of appetite have highest mean score [ESAS & EORTC QLQ-C30]. Compared to general population, APC patients' fatigue, pain, and appetite loss were significantly impaired [EORTC QLQ-C30]. b) Follow-up: increasing intensity of all symptoms the last 8 weeks before death, except for pain at rest and appetite [ESAS].
Laird (2011)	To examined whether pain, depression, and fatigue exist as a symptom cluster in advanced cancer patients with cachexia and might be related to the presence of systematic inflammation	Quantitative; comparative descriptive study	Cachectic, advanced, unresectable cancer (n=654; n of APC: 181)	**Timing dimension of symptom:** a) Pain, depression, and fatigue is an identifiable symptom cluster in a cohort of cachexic cancer patients. The prevalence of symptom cluster of pain, fatigue and depression is greater in lung and GI cancer than APC [EORTC QLQ-C30]. **Associating factors:** b) For all patients, Pain, depression, and fatigue symptom cluster was associated with reduced physical functioning, but not related to CRP.
Moningi (2015)	To evaluate how QoL change based on clinical stage at presentation to the JH Pancreas Multidisciplinary Clinic	Quantitative; descriptive study	Patients visited the Johns Hopkins Pancreas Multidisciplinary Clinic (n=77; n of APC: 39)	**Symptom intensity:** a) APC patients had significantly worse indigestion, flatulence, and diet limitations than patients with non-advanced stage [EORTC QLQ-PAN26]. **Associating factors:** b) Patients with lower performance status had significantly worse pancreatic pain and digestive symptoms.

Muller (2008)	To evaluate a palliative surgical bypass procedure in patients with obstructive and intraoperative pancreatic cancer	Quantitative; quasi-experimental study	Non-resectable pancreatic cancer (n=136)	**Symptom intensity:** a) Baseline: 26% patients had moderate- to severe- pain. **Timing dimension of symptom:** b) Baseline: 51% patients had daily pain **Associating factors:** c) Daily pain associated with significant poor survival after bypass surgery and was a significant independent indicator of poor survival.
Reyes-Gibby (2007)	To assess symptoms of patients with locally advanced pancreatic cancer receiving chemoradiation to determine the prevalence, and co-occurrence, of symptoms and to identify the extent to which symptoms interfered with function	Quantitative, descriptive correlational study	Locally advanced pancreatic cancer (n=43)	**Symptom intensity:** a) Baseline: 95% of patients reported at least one of the 13 symptoms. The most commonly reported symptoms of moderate to severe intensity were lack of appetite (24%), pain (19%), fatigue (19%), and sleep disturbance (10%) [MDASI]. b) Follow-up: An increase in patients reporting moderate to severe fatigue, nausea, and sleep disturbance during chemoradiation. The proportion of patients reporting moderate to severe symptoms of pain, lack of appetite, fatigue and sleep disturbance significantly decreased after 94 days of chemoradiation. **Associating factors:** c) Presence of a comorbid medical condition was a significant factor for symptom intensity. Lack of appetite, fatigue, sleep, and pain were the symptoms that accounted for variation in walking, activity, mood and enjoyment of life.
Romanus (2012)	To evaluate health-related QoL in patients with APC participating in a multicenter, double-blind, randomized trial	Quantitative; quasi-experimental study	Inoperable pancreatic cancer with ECOG status of 0-2 (n=186)	**Symptom intensity:** a) Baseline: compared with the U.S. general population, a larger proportion of APC patients reported problems in pain/discomfort (78%) and anxiety/depression (53%) [EQ-5D]. b) Follow-up: symptoms of anxiety/depression and pain/discomfort improved.
Seicean (2013)	To evaluate the safety and efficacy of EUS-CPN in patients with painful unresectable pancreatic cancer	Quantitative; quasi-experimental study	Inoperable, chemo-naïve body-tail pancreatic cancer receiving opioid analgesia (n=32)	**Symptom intensity:** a) Follow-up: pain improved significantly in 75% patients [BPI]. **Associating factors:** b) After procedure, ratings of "pain interfering with general activity, walking, work, mood, enjoyment of life, relations with others, and sleep" improved significantly. Physical, functional, and emotional well-being also improved significantly [FACT].
Stefaniak (2005)	To compare the effectiveness of two	Quantitative; quasi-	Inoperable	**Symptom intensity:**

	invasive pain treatments (NCPB & VSPL) to a control group concerning pain and QoL	experimental study	pancreatic cancer with pain (n=59)	(a) Follow-up: Both methods of invasive pain treatment resulted in significant reduction of pain and fatigue. **Associating factors:** (b) Physical, emotional and social well-being improved significantly only in NCPB group.
Walter (2011)	To compare QoL of patients with APC who were given palliative resection or double loop bypass surgery	Quantitative; quasi-experimental study	APC (n=196)	**Symptom intensity:** (a) Baseline: the average intensity level of appetite loss, insomnia, pain, fatigue, dyspnea, constipation, and diarrhea is moderate. (b) Follow-up: Palliative resection group had significantly increased dyspnea at discharge; increased nausea, dyspnea, constipation, and diarrhoea at 3 months after surgery. Appetite loss was more aggravated in double loop bypass group at 6 months after surgery.

Abbreviations: APC, advanced pancreatic cancer; ECOG, Eastern Cooperative Oncology Group performance; ESAS, Edmonton Symptom Assessment Scale; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer core module; EORTC QLQ-PAN26, European Organization for Research and Treatment of Cancer pancreatic cancer module; EQ-5D, European Quality of Life-5 Dimensions; FACT, Functional Assessment of Cancer Therapy; EUS-CPN; Endoscopic ultrasound-guided celiac plexus neurolysis; MDASI, M.D. Anderson Symptom Inventory; NCPB, neurolytic coeliac plexus block; JH, Johns Hopkins; VSPL, videothoracoscopic splanchnicectomy; QoL, quality of life.

Table 2-2. Symptoms Measured by EORTC QLQ-30/Pan26, EQ-5D, ESAS, FACT-G/Hep, and MDASI

Instruments / Symptoms	EORTC		ESAS	EQ-5D	FACT		MDASI
	Core module (QLQ-30)	Pancreatic cancer module (PAN26)			General module (G)	hepatobiliary module (Hep)	
Pain	X	X	X	X	X	X	X
Loss of appetite	X					X	X
Fatigue/ lack of energy	X		X		X	X	X
Sleep	X						X
Respiratory	X		X				X
Oral dryness		X				X	X
Test change		X				X	
Digestive[a]	X	X	X		X	X	X
Numbness							X
Senses of well-being			X		X		
Anxiety			X	X			
Depression/ sadness	X		X	X	X		X
Emotional distress/ mood disturbance							X
Life enjoyment							X
Fear	X	X					
Worry	X				X		X
Drowsiness			X				X
Satisfaction	X				X		
Hope					X		

Abbreviations: EORCT, European Organization for Research and Treatment of Cancer; ESAS, Edmonton Symptom Assessment Scale; EQ-5D, European Quality of Life-5 Dimensions; FACT, Functional Assessment of Cancer Therapy; MDASI, M.D. Anderson Symptom Inventory.

[a] Digestive symptoms includes nausea and vomiting, flatulence, altered bowel movement and indigestion

Table 2-3. Symptoms and Problematic Symptoms Identified by Reviewed Studies and Corresponding Instruments[a]

		Bye	Labori	Braun	Gao	Larid	Allen	Moningi	Walter	Stefaniak	Crippa	Seicean	Reyes-Gibby	Romanus	Dobratz	Muller
Physical	Pain	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
	Loss of appetite	X	X	X	X	X	X						X			
	Fatigue/ lack of energy	X	X	X	X	X	X		X	X		X	X			
	Sleep			X	X	X	X					X	X			
	Respiratory			X	X	X	X						X			
	Oral dryness	X	X										X			
	Test change	X														
	Digestive[b]	X	X	X	X	X	X	X				X	X			
	Numbness												X			
Psychological	Senses of well-being	X	X							X						
	Anxiety	X	X											X		
	Depression/ sadness	X	X						X			X	X	X		
	Emotional distress/ mood disturbance												X			
	Life enjoyment											X				
	Fear of future health problems							X								
Instruments		• EORTC QLQ-C30 & PAN26 • ESAS		EORTC QLQ-C30			• EORTC QLQ-C30 & PAN26 • BPI	EORTC QLQ-PAN26	EORTC QLQ-C30	• EORCT QLQ-C30 • FACT-G	• FACT-G • FACT-Hep	• FACT-G • BPI	MDASI	EQ-5D	McGill Melzack Pain Questio-nnaire	Single item of pain intensity and frequency
Operational definition of intensity levels		[EORTC] Moderate: ≥33.3; Severe:≥66.7 [ESAS] Moderate-severe: ≥4		[EORTC] Moderate: ≥33.3; Severe:≥66.7					Pain, fatigue, and depression respectively: Moderate: ≥	-	-	[BPI] moderate: 4-6; severe:≥7	Moderate-severe: ≥5	-	-	-

				50, ≥ 60, ≤70 Severe: ≥60, ≥70, ≤50							
Determination of the relatively problematic symptoms	More than half reported moderate- to severe-intensity	Moderate intensity on ESAS or EORTC	Moderate intensity on EORTC	-	-	-	-	Top 3 highest mean score	Symptoms reported by more than half of the patients	-	-

Abbreviations: BPI, Brief Pain Inventory; EORCT QLQ-C30, European Organization for Research and Treatment of Cancer core module; EORCT QLQ-PAN26, European Organization for Research and Treatment of Cancer pancreatic cancer module; EQ-5D, European Quality of Life-5 Dimensions; ESAS, Edmonton Symptom Assessment Scale; FACT-G, Functional Assessment of Cancer Therapy general module; FACT-HEP, Functional Assessment of Cancer Therapy hepatobiliary module; MDASI, M.D. Anderson Symptom Inventory.

[a] Shading cells represent relatively problematic symptoms

[b] Digestive symptoms includes nausea and vomiting, flatulence, altered bowel movement and indigestion

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CHAPTER THREE

This chapter included data on the symptom experience of patients with APC and their caregivers as told to their healthcare providers (dissertation aim 2). This sub-study aids in understanding the complexities of the symptom experience of APC patients and caregivers and how they expressed their concerns and feelings.

Symptom Experiences in Patients with Advanced Pancreatic Cancer as Reported During Healthcare Encounters

Pancreatic cancer is a prevalent and deadly form of cancer that is associated with a variety of severe and troubling symptoms. In 2016, an estimated 47,780 persons died from pancreatic cancer in the United States, making it the fourth leading cause of cancer deaths among adults.[3-1] In contrast to the decreasing mortality rates for most other types of cancer, the death rate of pancreatic cancer has increased gradually over the past decade, and scientists predict it will be the second leading cause of cancer deaths by 2030. [3-2] Due to the lack of effective prevention, early detection, and treatment interventions for pancreatic cancer, [3-3] less than 20% of patients are diagnosed at localized stage when they may be eligible for potential curative surgery, and the overall five-year survival rate for patients with advanced pancreatic cancer (APC) is about 1-3%.[3-1]

Patients with APC often experience multiple distressing symptoms. Symptoms are perceived indicators of change in normal functioning as experienced by patients. [3-4] An integrative review of 16 studies published between 2005 and 2015 revealed that patients with APC experience a variety of symptoms including pain, fatigue/lack of energy, loss of appetite, dry mouth, taste change, digestive problems, respiratory problems, and poor sleep, with fatigue, loss of appetite, and pain being the top three severe symptoms reported. [3-5] Psychological symptoms included impairment in a sense of well-being, depression, and anxiety. Some studies reveal that patients with APC have higher rates of psychological distress than patients with other types of cancer. [3-6-3-8]

Patients with APC often experience a rapid transition from a healthy status to the terminal stage of their illness, which is a stage which is often marked by significant symptom burden. Optimal symptom management is particularly critical at the end of life as symptom experiences are closely linked to functional status, health related quality of life, good death, and decision making.[3-4, 3-9-3-11] Despite that effective symptom management is a primary healthcare goal for patients with APC, physical and psychological symptoms are often unrecognized or poorly managed by healthcare providers.[3-12-3-14] For example, one study revealed that patients with pancreatic cancer and their caregivers received little information regarding eating and digestive problems during their clinical visits, prompting them to seek information on their own. Moreover, these uncontrolled symptoms contributed to unresolved grief in bereaved caregivers.[3-13]

Improving symptom recognition and management for patients with APC calls for a better understanding of how patients experience their symptoms. While studies have identified physical and psychological symptoms that are common in this population, little is known about the symptom experiences of patients with APC from the patients' perspectives and the perspectives of those who care for them. One source of information that can shed light on symptom experiences among patients with APC are the descriptions of symptoms offered by patients and their caregivers in the context of naturally occurring office visits with healthcare providers. The purpose of this study is therefore to examine recorded healthcare encounters between patients with APC, their caregivers, and healthcare providers to better understand the symptom experiences of patients with APC as told to their healthcare providers. The study is based on the assumption that while not all aspects of patients' symptom experiences would be revealed to healthcare providers, patients and caregivers are likely to reveal information regarding symptoms that are alarming, bothersome, or distressing. Understanding what is salient in the symptom experiences of patients with APC can provide a foundation for the development of strategies by which healthcare providers can facilitate symptom discussions and manage symptoms that matter most to patients and their caregivers.

Method

A qualitative descriptive (QD) approach was used for this study. QD studies provide a fundamental and low-interpretive description of the phenomenon of interest rather than a highly interpretive rendering of the data.[3-15, 3-16] This approach is widely used in health research when a pragmatic description of patient experiences is needed to address important practice issues.[3-16-3-18] Because we sought a straightforward description of how patients with APC experience symptoms, a QD approach was determined to be the most applicable method.

Sampling

The data for this study were drawn from transcripts of dialogue that occurred among patients with APC, their caregivers, and their healthcare providers during regular office visits. These encounters had been recorded for a large randomized controlled trial called the Values and Options in Cancer Care (VOICE, National Cancer Institute, R01CA140419, Clinical Trials Identifier: NCT01485627). The goal of the VOICE study was to test interventions designed to facilitate communication and decision making during healthcare encounters. Patients with stage three or four solid tumor cancers, their caregivers, and their oncologists were recruited from multiple oncology practices and cancer centers in the Rochester/Buffalo, NY and Sacramento, CA regions (2013—2015).

A total of 383 patients and 276 caregivers participated in the VOICE study, which is described in detail elsewhere. [3-19]

One office visit of the participating patients and, when available, their caregivers was recorded before the intervention and one was recorded following the intervention. On the day of the visits to be recorded, the research assistant met the participants in the waiting room, accompanied them to the clinic room, obtained verbal permission to record the visits, and activated two audio recorders before leaving the room. The research assistant collected the recordings after the visits and sent them to a professional medical transcription service. Because the aim of the current study was to explore how patients with APC experience symptoms, we chose to use only transcripts of pre-intervention visits so we could examine the most naturally occurring symptom discussions. Thirty-seven transcripts of pre-intervention visits were available for patients with APC.

Data Analysis

Standard content analysis was used to analyze the data. [3-20] The data were analyzed by three nurse researchers with expertise in oncology nursing and qualitative methods. The NVivo qualitative data analysis software (version 10; QSR International Pty Ltd, 2012) and Microsoft Word (version 2609; Microsoft Office 365 ProPlus, 2016) were used to aid the analysis.

The analysis was completed in six steps: (1) All members of the analysis team read through the transcripts to become familiar with the overall nature of all of the encounters; (2) The first author wrote a brief case description of each encounter; (3) The first author extracted and highlighted any text units [e.g., words, phrase, sentences] in which a patient or caregiver discussed the patient's symptoms and labeled each with a code, which is a short phrase that captures the meaning of the text; (4) The second and third authors reviewed the case descriptions and verified the accuracy of the codes; (5) The first author constructed a descriptive table to organize, condense, and display the codes into categories. [3-21] The table was examined and discussed by the team in regularly scheduled meetings; and (6) The first author wrote a narrative description of the categories and how each category relate to the study aims.

Results

The results are based on the verbatim transcripts of 37 healthcare encounters between patients with APC, their caregivers, and their healthcare providers. Twenty-two of the encounters included the patient, a caregiver, and an oncologist; seven included the patient, a caregiver, an oncologist, and a nurse; five included the patient and an oncologist; two included the patient, a caregiver, a nurse, and two oncologists; and one included the patient, an oncologist, and a nurse (table 3-1). The encounters generally lasted between 5 and 54 minutes.

As the focus of this analysis was on the patients' symptoms as described by the patients and their caregivers, the sample includes 71 persons - the 37 patients and 34 caregivers present during the encounters. The mean age of the patients was 66, ranging from 44 to 92. Twenty-one patients were females and 16 patients were males. Thirty-three of the patients were receiving chemotherapy at the time of the encounter. One patient was receiving supportive care, and one was receiving hormone therapy. The type of treatment that two of the patients were receiving was unclear. Among the 34 caregivers, 21 were spouses, 6 were children, 3 were siblings, 3 were friends, and 1 was the mother of the patient (table 3-2). In this paper, we use the term participants when we are referring to the patients and the caregivers together, whereas we use the terms patients and caregivers when we are referring to each group separately.

During the encounters, the participants discussed a variety of symptoms that ranged from mild to severe or life-changing. At times, the participants initiated the symptom discussion on their own or in response to general provider questions (e.g., How are you feeling?), and at times the symptom discussion was in response to specific questions asked by the provider (e.g., No problem with eating?). When discussing the patients' symptoms, the participants addressed three main topics: how the patients experienced their symptoms, the effect of the symptoms on their everyday lives, and the strategies the patients and the caregivers used to manage the patients' symptoms. During the encounters, the participants identified 10 major types of symptoms: pain, fatigue, abnormal bowel movements, decreased appetite, nausea and vomiting, sleeping problems, neurological problems, skin problems, taste changes, and psychological distress. How the participants described each of these 10 types of symptoms in regards to the three main topics are described below, with verbatim quotes included as examples.

Pain

In 33 of the encounters, the participants discussed the symptom of pain. While some patients indicated that they had had pain but that it had improved or was mild, some participants pointed out that the patients experienced on-going pain with the intensity varied greatly. A 57-year-old woman said, “And I mean like to the point where it would wake me out of a dead sleep I was in so much pain.” Some patients indicated that they experienced constant pain whereas others said that their pain was intermittent. A few participants were asked to rate the level of patients' current pain using a 10-point scale; these participants rated the patients' pain between 3 and 6.

Patients reported several different pain locations, although most often the pain was in the abdominal area. Some pointed out that their pain was located in upper-right abdomen or the "liver" area, whereas others said that the location of their pain was vague or that it "hops around." Some said they had a "stomach ache," and others described their abdominal pain as tender, cramping, sore, sharp, or piercing. The patients also described pain in other areas of their body. Some participants mentioned the patients' had chronic back pain, and some patients discussed bone and joint pain in their hips and knees. One patient said that he had an "achy" pain in his joints. A few participants mentioned the patients' muscle pain, injection-related pain, and chest pain.

Many participants attributed patients' pain to the growing of the pancreatic cancer. Other participants suggested other factors, such as injections, blood production, depression, overeating, a hernia, reflux, an ulcer, radiation, and even the weather, contributed to the patients' pain. Some patients attributed their joint pain to chemotherapy as they experienced the pain following a treatment.

Many participants shared how the patients' pain was affecting their lives. Some patients stated that they could still perform daily activities despite the pain, while others said it interfered with normal activities. A 47-year-old woman with pain around her waist was limited in what she could wear. She said, "I mean a lot of it is I can't wear anything with. . . anything on the waist." Some patients revealed their pain interfered with their sleeping. Both the patients and caregivers indicated that the pain was distressing. Several participants revealed, however, that they also worried about the side-effects of pain medications. A 74-year-old man said, “But then I was afraid to take any more of the Oxycodone for fear of getting nauseated again.”

The participants discussed a number of strategies they used to manage pain. Most talked about using pain medications, including opioids, nonsteroidal anti-inflammatory drugs, acetaminophen, or drug combinations. Some patients reported that they took long-acting pain medications around the clock plus short-acting medications for breakthrough pain. Other patients stated that they took pain medications only when they experienced pain or before special events. Some patients said that they cut back on pain medicines due to constipation or dislike of pain medicines generally. A 56-year-old woman said, “I don’t like pain medicine so I really. . . you know, I try not to take them unless…I need it.” Some patients mentioned that the chemotherapy was effective in alleviating pain while others discussed adjusting their chemotherapy schedule or stopping chemotherapy due to worsening pain. A few participants talked about the patients’ celiac plexus block and using strategies to improve patient comfort, such as applying ice or wearing loose fitting clothing.

Fatigue

In 29 of the encounters, the participants discussed the symptom of fatigue. While some stated that the patient’s fatigue was improved, tolerable, or fluctuating, many stated the patients endured severe or constant fatigue. The participants described fatigue in different ways; they stated the patients were fatigued, tired, had low energy, slept a lot, and had difficulty carrying out daily activities. One woman said that her husband “just can’t get himself out of the bed.” A few patients reported that they felt weak, “down,” or slow. Some participants were asked by providers to rate the level of the patients’ fatigue using a 100-point scale with higher score indicating more fatigue; the score ranged between 60 and 70. On the other hand, some participants used a 100-point scale to rate the level of patient's activity level with higher score indicating more active; the score ranged between 70 to 90.

Many participants attributed the patients' fatigue to chemotherapy as the fatigue typically began within hours to three days of receiving chemotherapy and improved on the fourth or fifth day. A 81-year-old man said, "You know, after the chemo a couple of days I'm not. . . that, I just feel sluggish." However, a few participants indicated that the patients' fatigue continued more than a week after chemotherapy and even got worse. A few participants suggested that other factors, such as aging, infections, diarrhea, dry mouth, or acid reflux, may contribute to the patients' fatigue.

Many participants shared how the patients' fatigue was affecting their lives, especially the ability to do daily activities. Participants pointed out that the patients either slept all day or took naps during the day and this interfered with their night-time sleeping and their eating schedule. Some patients discussed how their ability to work or exercise was impaired. A 66-year-old man said, "If I'm out working on the car in the garage and I work for a few hours I get really tired. I'll come in and that's it. The next day I feel like I'm wiped out." A few participants stated that the patient's fatigue interrupted their travel plans.

Both the patients and caregivers indicated the fatigue were distressing. Some patients revealed that they were "hit" by fatigue. One 56-year-old woman said, "Just the worst thing is the fatigue." Some caregivers disclosed that they were quite bothered about the patients' fatigue. One caregiver, whose husband was so tired that he slept nearly all day, complained that their life had changed dramatically. She said, “He’s not even with me… it’s like cancer is married to him now and I’m not. So, the cancer is with him all the time and I’m [along] in the room.” In some instances, the patients and caregivers described the fatigue differently. For example, when one patient stated that his fatigue was not too bad, his wife interrupted him saying that she did not like him being so fatigued. Another patient decided to discontinue chemotherapy due to fatigue even though she knew that her family disagreed with this choice.

The participants identified a number of strategies they used to manage fatigue. Some participants discussed adjusting the patients’ chemotherapy schedule, and a few patients questioned the necessity of continuing chemotherapy as they became weaker. Some participants mentioned that the patients slept more to restore energy and walked or exercised to relieve their fatigue. Patients discussed using medications to increase their energy, trying to eat “healthy” to combat the fatigue, or setting up eating plan if they were too tired to eat. A few patients discussed being admitting to the hospital to manage the severe fatigue or receiving a blood transfusion to manage fatigue or fatigue-related problems.

Abnormal Bowel Movements

In 26 of the encounters, the participants discussed the symptoms of diarrhea and/or constipation. While some participants described the patients’ bowel movement as natural, good, regular, or solid, other patients complained of diarrhea, constipation, or both. Some patients described diarrhea or “loose stools” that ranged from mild to severe, and some indicated that the intensity and frequency of diarrhea fluctuated. A few patients reported that they experienced diarrhea continually through the day and night and needed to spend much time in the bathroom. One patient referred to her diarrhea as “morning sickness” because she typically experienced it in the morning. Another patient described abdominal pain that occurred with the diarrhea. Many participants attributed the diarrhea to chemotherapy, and one caregiver suggested it was due to an infection. Fewer patients discussed constipation, but those that did described it as aversive or “terrible” and often attributed it to their pain medicines. One patient described changes in the appearance of stool and described it as having an “ugly greenish stool which does not look good.” In some instances, there was inconsistency in how the patients and caregivers described changes in bowel movements or how bowel movements were described at different points in the encounter. For example, one patient said that he had no problem with bowel movements, whereas his caregiver said he had had several episodes of irritating diarrhea. Later in the encounter, the patient revealed that he had in fact had frequent diarrhea during the past month. In another instance, in the beginning of the encounter the participants described the patient’s bowel movements as regular but later indicated that he had experienced both diarrhea and constipation.

Many participants shared how diarrhea and constipation were affecting the patients’ lives. Some patients revealed that the diarrhea interrupted their sleep and daily activities. For example, one patient mentioned that the diarrhea kept her close to home and prohibited her from enjoying outdoor activities. Another 74-year-old male said, “I had the buffet and all that and I couldn’t even eat the buffet because every couple of minutes I had to go to the bathroom.” One caregiver said that her husband’s diarrhea contributed to his fatigue. Many participants expressed that diarrhea and constipation caused psychological distress, fear, and irritation. One patient stated that he could “live with” his diarrhea, and another said that having frequent bowel movements was better than being constipated.

Participants discussed several strategies that they used to manage the patients’ diarrhea and constipation. Most talked about the patients taking anti-diarrhea drugs or stool softeners that had varying degrees of effectiveness. A few participants requested advice from the healthcare provider about how to manage these symptoms. One patient mentioned that he could not manage his constipation by drinking fluids, and another patient requested longer rest periods between chemotherapies due to his diarrhea. One patient asked the oncologist to prescribe medicine to prevent diarrhea, and another patient described how she took fewer iron supplements that cause constipation.

Appetite Change

In 23 of the encounters, the participants discussed the symptom of appetite change. While some stated that the patient’s appetite was good or had improved, others described the patient’s appetite as poor or decreased. Some participants indicated that the patients ate nearly nothing. For example, one caregiver stated that her husband “eats like a bird.” A few participants indicated that the patients were not able to eat as much as they once did. An 80-year-old woman said, “Like I just had lunch at the Char Broil and I ate half of what I used to eat.” A few caregivers pointed out that the patients’ appetite problems were on-going. Some patients attributed their appetite change to nausea and vomiting, and one caregiver said that her husband’s appetite change occurred after chemotherapy.

Many participants shared how the patients’ appetite change was affecting their lives, especially their eating and their weight. One patient questioned if his appetite change was related to his cancer spreading. Both the patients and caregivers indicated the patients' appetite changes were distressing. Several caregivers, for example, revealed that they became frustrated when the patients would not eat. Conversely, one caregiver indicated that she felt "proud" when her husband ate well.

The participants discussed a number of strategies they used to manage appetite changes. Some described "force-eating," that is, the patients tried to eat regardless of their appetite. Others mentioned strategies such as taking pancreatic enzymes, using steroids, identifying the patient's favorite food, eating small and frequent meals, and setting eating goals. Several caregivers said that they tried to identify foods that patient would be interested in eating. For instance, one caregiver mentioned how she purchased all of the cookbooks recommended by the dietician in order to prepare food that would improve her husband's appetite. One patient pointed out that she closely monitored her weight, and one caregiver shared how she consulted with a nutritionist about her husband's eating problems.

Nausea and Vomiting

In 20 of the encounters, the participants discussed the symptoms of nausea and/or vomiting with their healthcare providers. They described nausea that ranged from none to "a small touch" to severe. In some cases, the nausea was accompanied by vomiting, and some participants reported when and how long the patients vomited. For example, one caregiver indicated that he considered his wife's nausea to be severe because it lasted over a week. Many participants revealed that the nausea and vomiting occurred during or the couple of days after chemotherapy. Several mentioned that these symptoms arose after the patients ate. One patient mentioned experiencing relief after vomiting because the food was just “sitting there.” Other participants attributed the nausea and vomiting to other causes. One indicated that the nausea was triggered by pain medicine, whereas another indicated that the symptoms were due to an infection. One patient mentioned that she became nauseous when brushing her teeth.

Many participants shared how nausea and vomiting were affecting the patients’ lives. For some patients, these symptoms impacted their daily lives profoundly. Many patients revealed that the nausea and vomiting brought uncertainty, worry, and fear. They talked about being worried about throwing up important medications and being afraid of taking pain medications that could trigger nausea. One patient stressed that the severe vomiting “set back [his] life” and questioned the value of taking so many medicines when he continuously experienced severe vomiting as a result. Several mentioned that nausea and vomiting affected their eating, especially of foods that triggered these symptoms. Some described how nausea and vomiting impeded their daily activities such as working or doing housework. One 56-year-old woman mentioned that the medication she was given for nausea affected her life as its sedation effects isolated her and prevented her from doing daily activities. She said, “It [Compazine] puts me into a very different type of state like where I’m almost not aware of someone maybe coming in the front door.” Her caregiver stated that taking Compazine made the patient “sleep like a zombie.”

Participants discussed several strategies that they used to manage the patients’ nausea and vomiting. Most talked about the anti-nausea drugs taken by the patients but indicated these drugs were not always effective and were sedating. A few participants mentioned the strategy of “forced-eating,” which was trying hard to eat and holding things down regardless of the nausea. One patient requested to postpone chemotherapy because of severe vomiting.

Sleep Problems

In 17 of the encounters, the participants discussed problems with sleep. Many revealed that the patients had poor sleep quality, including difficulties falling asleep, waking up during the night, and confusing day and night. A 62-year-old man said, “I’d wake up at 1 in the morning and I am awake. So, I get up, sit. I didn’t want to turn the [light] on to get stimulated so I just sit for an hour, lay back down, wake up again at 4. So it was a terrible pattern.” Some patients indicated that these sleep problems lasted for some time. Many participants attributed the patients’ sleeping problems to other symptoms such as pain, diarrhea, and psychological distress. Some participants indicated that due to fatigue the patients slept nearly all day and thus could not sleep at night. One patient, for example, said that he slept poorly at night because he took frequent naps during the day. One patient suggested that aging affected his sleep.

Many participants shared how sleep problems were affecting the patients’ lives. One patient reported that he could not drive because he was using sleeping pills. Other participants revealed that their sleeping problems or the need for sleeping medications caused psychological distress. A 73-year-old man said, “I hate to use it [drug] because I can’t hardly wake up the next day.” A few caregivers articulated their frustration and worry about the patients sleeping too much or using sleeping pills.

Participants discussed some strategies that they used to manage the patients’ sleeping problems. Most talked about the sleeping pills the patients used. Some participants reported that sleeping medications helped the patients sleep well at night, whereas others reported sleeping medications were not effective. Some participants reported that using effective strategies to manage related symptoms, including pain and diarrhea, would help the patients' sleep. A few participants described trying to keep themselves awake during the day so they could sleep better at night.

Neurological Problems

In 15 of the encounters, the participants discussed neurological symptoms. Some participants referred to these symptoms as "neuropathy." Many revealed that the patients experienced abnormal sensations, including tingling and/or numbness in fingers and toes, sensitivity to cold, insensitivity to pressure, and sensitivity in their mouths or hands. For instance, a 60-year-old woman described that she had "a little bit of tingling in my fingers." She said, "It's just like when I grab something out of the freezer or refrigerator." Most participants indicated that these abnormal sensations were mild or intermittent and often resolved within hours to a week after chemotherapy. Some patients reported other types of neurological symptoms such as balance issues, dizziness, and blurred vision.

Many participants shared how neurological symptoms were affecting the patients' lives. Some patients described needing the help of others because they had difficulty writing and holding things. A couple of participants reported that eating and drinking were problematic. For example, one patient stated that because he could not tolerate drinking cold liquids, he could not take dietary supplements although he had a poor appetite and significant weight loss. Some patients indicated that their neurological problems had caused minimum disruption, and one patient said that he was learning to live with the numbness.

Participants discussed some strategies that they used to manage the patients' neurological problems. Some patients talked about taking vitamins or supplements to strengthen neurological function or being mindful about their balance problems to prevent falling. A 67 year-old man said, “I have to watch my balance a little bit.” A few patients talked about getting assistance from others to carry out tasks, eating food at room temperature, and wearing glasses for vision changes.

Skin Problems

In 13 of the encounters, the participants discussed skin problems, including problems with their hair and nails. They discussed skin rashes, dry skin, and itching. Many revealed that patients experienced severe rashes on their hands, arms, or faces during or after chemotherapy. A few patients mentioned their skin rash or “red sole” had slowly improved. Several participants said that patients had dry or “rough” skin, especially on their hands. Some patients reported that they experienced severe itching all over their body. One patient pointed out that the itching typically occurred at bedtime. A few patients described other uncomfortable skin sensations. One patient stated that she felt “stingy,” and another complained that her knuckles were uncomfortable. Although most participants attributed skin problems to chemotherapy, a few caregivers suggested it was due to other causes such as exposure to sun or poison ivy. One patient pointed out that his skin rash was caused by scratching.

Many participants revealed that the patients' hair and/ or nails were affected. Some patients described the loss of some or part of their hair or toe nails, and others described the fragility or abnormal appearance of their hair and nails. For example, one patient said that she had “shabby” nails and revealed that her hair was “coming out in clumps.”

Many participants shared how skin problems were affecting the patients’ lives. Some patients complained that itching interfered with their sleep. While one patient stated that he kept scratching during sleep, his wife pointed out that she believed that the pruritus drug facilitated his sleep. Several participants said they felt shocked, bothered, or irritated by their rash or itching. A 65-year-old woman mentioned, “My only thing is I would want to know what to do about these little things [rash] that become irritants.” A few patients stated that they were distressed about hair loss. A 81-year-old woman said, “I want a family picture before I lose it all.” In some cases, patients and caregivers differed in their reports of the severity of the skin problems, especially hair loss. For example, patients reported feeling depressed about her hair loss but were reluctant to wear a wig, whereas their caregivers denied the depression and encouraged them to wear a wig.

Participants discussed several strategies they used to manage the patients’ skin problems. Many mentioned consulting with dermatologists, using medication for their rashes, and keeping their skin moist. Some patients said that they just scratched their skin when itchy. A few patients talked about avoiding sun exposure or protecting fragile nails. Several indicated that they got a wig when they lost their hair.

Psychological Distress

In 12 of the encounters, the participants discussed various types of psychological distress. Some participants indicated that the patients experienced anxiety and fear about their own health and the welfare of their families due to the seriousness of the illness.

One 42-year-old woman said,” I just [worry about] my kids. My little guy. Because he has Down’s Syndrome. I'm worried. That he’ll forget me.” Participants revealed that some patients also experienced sadness or depression. Some patients cried when expressing these feelings. For example, one patient tearfully revealed that she was not prepared to discuss the progression of her disease because she “felt so good” at the present time. In some instances, caregivers minimized the psychological distress mentioned by the patients. For example, when a 56-year-old woman said that she was “down” for the whole day because of anxiety, her husband said, “I don't think it was [the anxiety] …Just that because when she crashes, she’s out.”

Many patients shared how their psychological distress was affecting their lives. Some patients indicated that their physical symptoms were worsened by their psychological distress. A 60-year-old woman attributed her stomachache to her anxiety. She asked, “I think maybe it’s [due to] nervousness, maybe, do you think?” Some patients indicated that their ability to process information and concentrate was affected by their psychological distress. An 81-year-old woman, when told that her chemotherapy was ineffective, said, “Well, I can’t think of anything… I haven’t heard half what you said.”

The participants discussed a number of strategies they used to manage their psychological distress. Most mentioned taking medications to manage their anxiety and depression. Some indicated that their psychological distress improved as a result of using drugs that were not originally prescribed for psychological symptoms. When discussing a chemotherapy regimen containing a steroid, a 56-year-old woman said, “But I found. . . no, it wasn’t bad. I mean I kind of. . . it [steroid] gave me a sense of well-being.” Some patients talked about consulting other physicians about their psychological distress, and a few stated that they had learned to accept it. One caregiver suggested to her mother that she write herself notes when her psychological distress got in her way of thinking clearly.

Taste Change

In seven of the encounters, the participants discussed the symptom of taste change. Some patients described how they had lost their sense of taste. A 56-year-old woman said, “My taste buds are shut.” Some patients said that they got a “bad taste” in their mouth during or after eating. One patient pointed out that he got bitter taste after eating, food did not taste like food, and he experienced the texture of food differently. Some patients indicated that taste change started at the beginning of the chemotherapy, typically lasted weeks after chemotherapy, and, in some cases, then returned to normal.

Many participants shared how taste change was affecting the patients’ lives. Some participants considered taste change as a main barrier of eating despite that the patients had good appetite. One 67-year-old man described constant pressure from his family to eat, which he found to be frustrating.

Some participants discussed several strategies that they used to manage the patients’ taste change. Some caregivers suggested that patients eat anyway, and some patients said that they tried to find food that was still enjoyable. One caregiver described how her added dietary supplements, and one patient disclosed that he had no idea how to deal with taste change.

Infrequently Mentioned Symptoms

There were some symptoms that were mentioned only in passing by a small number of participants. These symptoms included abdominal bloating, generalized discomfort, mouth sore, dry mouth, swallowing difficulties, indigestion, breathing problems, and hot flashes.

Discussion

The findings of this study describe how patients with APC experience their symptoms based on how they and their caregivers describe the symptoms to their healthcare providers during scheduled office visits. The participants discussed a variety of symptoms, including pain, fatigue, abnormal bowel movements, decreased appetite, nausea and vomiting, sleeping problems, neurological problems, skin problems, psychological distress, and taste changes. Many participants reported multiple symptoms including some that were severe or highly distressing. Although the participants attributed the patients’ symptoms to a range of factors, the most common were the worsening of the cancer and the side effects of treatments, especially chemotherapy. Many patients revealed that their symptoms affected their daily lives profoundly by interfering with their eating and sleeping, working, traveling, and self-care. They also reported that the symptoms could cause psychological distress and affect their cognitive functioning. In addition to taking medication to treat some of the symptoms, the participants indicated that the patients used a variety of strategies to manage their symptoms such as changing their eating habits to lessen their nausea, finding foods that appealed to them despite taste changes, applying ice to lessen pain, and exercising to combat fatigue. In some cases, they consulted with other healthcare professionals, such as nutritionists or mental health providers, about their symptoms. Some patients requested a modification or termination of chemotherapy because their symptoms had become unbearable.

These findings are consistent with quantitative evidence related to the variety and severity of symptoms experienced by patients with APC. For example, the symptom groups that emerged in our study overlapped considerably with the symptom groups revealed in the integrative review mentioned previously.[3-5] In fact, the symptoms discussed most frequently by our participants – pain, fatigue, and abnormal bowel movements – were similar to the top three severe symptoms revealed in the review – fatigue, loss of appetite, and pain. Moreover, our findings related to the attributions patients make about the etiology of their symptoms are consistent with findings from prior research. Just as we found that patients associated changes in their symptoms with the worsening of their illness, other researchers have reported that patients and caregivers view uncontrolled cancer pain as a sign of disease progression.[3-22, 3-23]

Our findings also confirm and extend the findings of other studies that address symptoms in cancer patients generally. Fatigue, for example, is reported to be a distressing symptom in the general cancer population.[3-24, 3-25] Our finding of the diverse description of fatigue (e.g., tired, low energy, can't get out of bed) is similar to a synthesis of qualitative research revealed that patients with a variety of types of cancer also describe their fatigue with a wide array of words and phrases (e.g., tired, weak, exhausted).[3-26] Similarly, just as the synthesis revealed that the physical and psychological impact of cancer-related fatigue is considerable,[3-26] our findings indicate that fatigue affects the lives of patients with APC in profound ways.

The recommendations stemming from prior studies that more attention be given to appetite and taste changes, which have been found to be problematic for both patients and caregivers,[3-27, 3-28] are consistent with our findings. Our findings also support other studies that have revealed that constipation, nausea, and vomiting interfere with cancer patients' lives in significant ways, affect their adherence to medication, and cause psychological distress. [3-29, 3-30] Although some of our participants were quite troubled by diarrhea as well, few studies have addressed the life disruptions caused by diarrhea from the perspective of the cancer patients. While many studies with cancer populations focus on peripheral neuropathy, [3-31] our participants discussed a variety of types of neurological symptoms as well as skin problems that may be overlooked in the literature. [3-5] Psychological distress, such as discussed by our participants, has been well documented, [3-6] although some studies focus more on physical rather than psychological symptoms. [3-5]

Other researchers have also reported that patients and caregivers often perceive the patients' symptoms differently. [3-32, 3-33] Whereas some studies indicate that caregivers tend to overestimate cancer patients' symptoms, [3-32, 3-34] the caregivers in our study contradicted the patients' descriptions of symptoms in a variety of ways, including challenging how the patients described the symptoms, pointing out symptoms to providers that the patients failed to mention, or suggesting the symptoms were not as bad, or conversely worse, than described by the patients.

Limitations

Our findings should be understood in the context of the study limitations. The major limitation is that we used a data set that had been established for another study. Although there was advantage to using recorded healthcare encounters because the symptom discussions occurred naturally rather than in the context of a retrospective research interview, we recognize that these recordings do not offer complete descriptions of patient symptom experiences. For example, the participants may have been reluctant to disclose psychological symptoms that could be stigmatizing, such as depression or suicidality, or may have neglected to mention minor, but nonetheless bothersome, symptoms that they assumed were not important enough to bring up. We also recognize that the questions providers ask or the interest they show in certain symptoms can influence the nature of symptom discussions during the encounters, but an analysis of the effects of provider behaviors on symptom discussions by patients and caregivers was beyond the scope of this report.

Future Research

While this study provides fundamental information on the symptom experiences of patients with APC, more studies are needed to obtain a comprehensive description of these symptom experiences as they unfold throughout the course of the patients' illness. Longitudinal studies in which patients and their caregivers journal symptom experiences over time, including how these symptoms are affecting their day-to-day lives, would overcome the primary limitations of our study. Such methods could obtain information on symptom experiences that might not be adequately addressed in healthcare encounters or in retrospective research interviews. Future studies could also examine how communication patterns between patients, caregivers, and providers influence how symptoms are addressed in healthcare encounters. For example, such studies could explore how healthcare providers and caregivers encourage or discourage the discussion of some symptoms by patients with APC.

Clinical Implications

The findings of this study suggest that healthcare providers should be attuned to the wide variety of ways in which patients with APC experience symptoms, how these symptoms affect their day-to-day lives, and how they and their caregivers attempt to manage their symptoms. Understanding symptom experiences from the perspectives of patients and caregivers will help providers appreciate what aspects of the symptoms experiences are most bothersome, what makes the symptoms become intolerable, and what assistance is desired in managing these symptoms. Soliciting patient and caregiver narratives about symptom experiences in addition to more structured assessments of the nature, severity, and course of the symptoms will allow providers to understand the role of symptoms in the context of the patients' day-to-day lives. This understanding will then inform the development of a comprehensive approach to symptom management.

Conclusions

To our knowledge, this is the first qualitative study to explore the overall symptom experience of patients with APC. Patients and caregivers discussed a wide range of symptoms during healthcare encounters and revealed that these symptoms could affect their lives in substantial ways. Our findings support prior research that identified symptoms most often experienced by patients with APC but extend these findings by providing descriptions of how these symptoms are experienced, how they affect the daily lives of patients and caregivers, and how patients and caregivers manage these symptoms. We argue that obtaining symptom narratives from patients and caregivers can reveal what concerns are most salient to them and that this information can inform their care.

Table 3-1.

Composition of the Participants in Healthcare Encounters (n=37)

	n	%
Patient, a caregiver, and an oncologist	22	59.46
Patient, a caregiver, an oncologist, and a nurse	7	18.92
Patient and an oncologist	5	13.51
Patient, a caregiver, two oncologists, and a nurse	2	5.41
Patient, an oncologist, and a nurse	1	2.70

Table 3-2.

Demographic data of Patients and Composition of Caregivers

	n	% or mean
Patients	37	100
Age	-	66
Gender		
Female	21	56.76
Male	16	43.24
Treatment type		
Chemotherapy	33	89.19
Hormone therapy	1	2.70
Supportive care only	1	2.70
Unclear	2	5.41
Caregivers	34	100*
Husband	8	23.53*
Wife	13	38.24*
Mother	1	2.94*
Daughter	5	14.71*
Son	1	2.94*
Brother	1	2.94*
Sister	2	5.88*
Friends	3	8.82*
Note. * Among all participated caregivers for advanced pancreatic cancer patients (n=34)		

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CHAPTER FOUR

This chapter describes sub-study 3 which explored how patients with APC and their caregivers interact with healthcare providers in regards to symptoms and symptom management (dissertation aim 3).

Patterns of Interactions Among Patients with Advanced Pancreatic Cancer, Their Caregivers, and Healthcare Providers During Symptom Discussions

Managing symptoms effectively is a primary goal for terminally ill patients, their caregivers, and healthcare providers. Patients with advanced pancreatic cancer (APC), who often have limited curative treatment options and can experience a rapid transition from healthy status to a terminal stage of their illness, have considerable physical and psychological symptom burden. [4-1] Evidence shows that symptom management is often problematic for this population, [4-2] and poorly managed symptoms can have a profoundly negative effect on the quality of life of patients with APC and their caregivers. [4-2-4-4]

Symptoms are often the major topic of conversations between cancer patients and providers. [4-5, 4-6] Effective symptom management is one of the critical outcomes of effective patient/caregiver and provider communication. [4-7-4-10] Research has shown that effective communication with providers can alleviate the psychological and physical symptom burden of patients in four ways: 1) encouraging expression, 2) evaluating the symptoms, their impacts, and the effectiveness of interventions, 3) providing support, and 4) enhancing self-management and perceived control over the symptoms. [4-7, 4-11, 4-12]

Despite its importance, a dearth of studies has addressed how patients, caregivers, and providers discuss symptoms and symptom management during healthcare encounters. A few studies, however, have shown that the quality of these symptom discussion might not be optimal. [4-13-4-15] For example, some research has indicated that cancer patients are often discouraged from expressing their feelings about their symptoms and their concerns about what the symptoms indicate. In one qualitative descriptive study that described interactions between providers and patients reporting cancer pain (n=84), researchers found that clinicians asked five times more close-ended questions than open-ended questions during symptom discussions and interrupted cancer patients in more than half of the symptom discussions. [4-16] Moreover, several studies have revealed that a significant number of cancer patients report that they have not discussed, or did not want to discuss, their significant symptoms with healthcare providers. [4-12, 4-17-4-19] Many cancer patients also report that they do not receive symptom management recommendations from healthcare providers. [4-12, 4-19] In a 2009 systematic review, Jacobsen and colleagues synthesized 37 studies with more than 6000 cancer patients that examined barriers to cancer pain management. They found that communication about pain was studied less than other factors, and that studies that did examine the quality of pain communication reported that it was often not satisfactory. More research is therefore warranted to understand patient/caregiver and provider communication regarding symptoms and symptom management.

The purpose of this study was to develop a typology to describe patterns of interactions between patients with APC, their caregivers, and healthcare providers in regards to symptoms and symptom management. The findings can provide foundational information needed to develop strategies to improve symptom discussions in healthcare encounters for this population.

Method

A thematic analysis of audio-recorded interactions between patients with advanced cancer, their caregivers, and healthcare providers during naturally occurring office visits was conducted.

Thematic analysis as described by Braun and Clarke (2006) was the method used in this study. Thematic analysis is widely used in health research to identify, analyze, and report patterns within data. [4-20] According to Braun and Clarke, a theme “captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set.” [4-20] Thematic analysis can be used flexibly as it allows researchers to determine themes that best answer their research questions.

Thematic analysis offers researchers several options for research design. First, thematic analysis can be used as an inductive or deductive approach. Inductive analysis is a data-driven and “bottom-up” approach in which themes are derived from empirical data. Deductive analysis is a theory-driven and “top-down” approach in which data are analyzed as they relate to themes drawn from established frameworks. Second, themes can be derived at the semantic or latent level. Semantic themes capture the explicit or surface level meanings of the data, whereas latent themes reflect the assumptions or concepts the underlie the data and give form to patterns of data. Our study was an inductive thematic analysis because we allowed the themes to emerge from the transcribed encounters rather than fitting the data into pre-determined themes drawn from a specific theoretical framework. Our themes were identified at the latent level as we did not just describe what the patients, caregivers, and providers said but instead interpreted the underlying meaning of the interactions.

Sampling

The Indiana University Human Subjects Office Institutional Review Board approved this study. De-identified transcripts of APC patients’ audio-recorded office visits were selected from a large randomized controlled trial called the Values and Options in Cancer Care (VOICE, National Cancer Institute, R01CA140419, Clinical Trials Identifier: NCT01485627). The VOICE study recruited patients with stage three or four solid tumor cancers, their caregivers, and their oncologists from New York and California regions (2013—2015) to test an intervention designed to facilitate communication and decision making. Detailed recruiting process and study methods were described elsewhere. [4-21] Although one pre-intervention visit and one post-intervention visit were recorded in the VOICE study, we only included and analyzed 37 transcripts of APC patients' pre-intervention visits to capture most naturally occurring interactions.

Data analysis

Three nurse researchers with expertise in oncology nursing and qualitative methods analyzed the data. The NVivo qualitative data analysis software (version 10; QSR International Pty Ltd, 2012), Microsoft Word, and Microsoft Excel (version 2609; Microsoft Office 365 ProPlus, 2016) were used to organize the data and facilitate the analysis. Following the guidelines suggested by Braun and Clarke (2006), the analysis was conducted in six phases. The six phases were as follows:

Phase 1: Familiarizing yourself with your data. All members of the analysis team read through the transcripts several times to become familiar with the overall nature of all encounters.

Phase 2: Generating initial codes. The first author extracted all data related to interactions that were pertinent to symptoms or symptom management. Interactions in which providers, patients, and caregivers worked out routine details of care or treatment (e.g., prescribing medicines, scheduling appointments) or engaged in small talk were not extracted. The first author then divided all dialogue into meaningful segments of text and coded each segment with a label that captures its essence.

Phase 3. Searching for themes. Each team member individually compared and contrasted the codes and organized common codes into themes.

Phase 4. Reviewing themes. The analysis team met on several occasions to review potential or "candidate" themes. Each team member presented the themes that they arrived individually to the group, discussed the essence of the themes, and shared examples from the transcripts that exemplified the themes. Through consensus and discussion, the team agreed on eight themes. Upon further discussion, the team determined that each of the themes reflected unique interaction patterns between providers, patients, and caregivers.

Phase 5. Defining and naming themes. The team met again to name each theme, or interaction pattern, to define the patterns, and to determine the core characteristics of each patterns. Using this information, the first author then returned to the data and placed each interaction in one of the eight patterns. The other team members verified the placement of the interactions by reviewing the transcripts.

Phase 6. Producing the report. The first author wrote a narrative report that described each pattern and provided exemplar that best reflected each pattern. The other team members reviewed and verified the report.

Results

Based on the transcripts of 37 healthcare encounters, the team identified eight themes that they determined reflected eight unique types of interaction patterns among patients, caregivers, and healthcare providers. The eight interaction patterns were as follows: collaborative interactions, explanatory interactions, agentic interactions, checklist interactions, cross-purpose interactions, empathic interactions, admonishing interactions, and diverging interactions. Most encounters included the patient, a caregiver, and an oncologist, and in some instances, a nurse. The encounters included 117 persons: 37 patients, 34 caregivers, 37 oncologists, and 9 nurses. The encounters lasted between 5 to 54 minutes. Most of the encounters included several of the interaction patterns. In some encounters, one pattern dominated the encounter, whereas in others, several patterns stood out over the course of the encounter. The interaction patterns, their defining characteristics, and exemplars of each are discussed below.

Collaborative Interaction Pattern

In 31 of the healthcare encounters, an interaction pattern occurred that we have labeled as collaborative interactions. Collaborative interactions are those in which the patients/ caregivers and providers worked together to figure out the nature of a symptom or a course of action. This interaction pattern typically had a “two-way” feeling and neither the patients and/or caregivers or providers dominated the conversations. During the conversations, the providers often acknowledged what patients or caregivers had said. In one interaction, for example, when the patient said he wanted to manage fatigue at home instead of staying at the hospital, his wife responded by saying, “Okay. I hear you. We’ll do it.” In several cases, the providers asked for input from patients or caregivers or began the interaction with an open-ended question. One provider began a collaborative interaction with the question, “How do you deal with exercise?” During the collaborative interactions, some patients expressed their trust in the providers and seemed to appreciate making decisions jointly.

An example of a collaborative interaction follows. In this interaction, a 73-year-old man, his wife, and the oncologist discussed discontinuing chemotherapy. Each contributed to this treatment decision:

Oncologist: But with the pain changing this much I am worried that the cancer might be growing, Mr. [Patient].

Patient: Well, that's what I said to my wife, is I don't know this chemo's working.

Oncologist: Right.

Patient: It just seems to be growing.

Oncologist: Right. I. . . I think so, too. You know, and I feel that -

Patient: Can we. . . can we prove that through tests somehow?

Oncologist: We can. It's not . . . doing scans at such short interval, you know, just a few weeks apart, sometimes the scans don't catch up to what's actually happening in the body which is why we have to wait, you know, six weeks or something. But if you think that it will help you decide that let's put this final chemo, you know, put to rest and know that it's not working then we'll do the scan. I. . . I don't know if we need the scan, Mr. [Patient], because, you know, everyone at home and we here who know you see the change. Right? You have never required a pain pill in clinic, right?

Patient: Yeah.

Oncologist: And so I think whether the scan shows growth that can be measured, you know, I don't know if that's. . . we need that. I think that I have enough evidence here for me to say that this chemo is not working.

Patient: Oh, okay. Unless. . .

Oncologist: Yeah, I think so.

Patient: I’ll go with the Lord.

Oncologist: Yeah, because I just. . .

Patient: I have a lot of good faith for the Lord and I carry him with me everywhere I go. Along with my. . . along with my navy anchor. [Laughter]

Oncologist: They go together, right?

Patient: Yeah, why don’t we just stop it.

Oncologist: Yeah, because if I felt that it was just the tiredness or if you were having some side effects we would come up with some way to get through. But I think that, you know, and we’ll have blood work, we’ll have some tests there.

Patient: Are you okay with that [to his wife]?

Caregiver: Hmm?

Patient: Are you okay with that?

Caregiver: It’s your decision. Your decision. I would say he was more tired this week than before. Honestly…

Explanatory Interaction Pattern

In 28 of the healthcare encounters, an interaction pattern occurred that we have labeled as explanatory interactions. Explanatory interactions are those in which the providers gave factual information to patients and caregivers. Providers typically initiated these interactions when they explained the patients' test results, disease progression, treatment options, or the cause of their symptoms. Sometimes the providers gave these explanations in response to questions by patients or caregivers. The providers often did most of the talking and patients and caregivers said little or interjected brief remarks. In some cases, the patients said little seemingly because the information given to them was upsetting, complicated, or shocking. For example, an oncologist explained the second line treatment options for a patient whose disease had progressed and whose symptoms had worsened. Following the explanation, the oncologist asked the patient if she had any questions, to which the patient replied "I haven't heard half what you said." Explanations of disease progression were at times followed by questions from patients and caregivers about life expectancy and options of surgery or radiation or discussions regarding preferences for maintaining quality of life versus continuing aggressive treatments. In one case, the provider explained that symptom management was the goal of treatment and that surgery was not an option.

An example of an explanatory interaction follows. In this interaction, an oncologist explained to a 73-year-old woman that her cancer was spreading and discussed her treatment options:

Oncologist: They [lymph nodes] are all less than 5 millimeters but they are new and they are increasing, which means that the cancer is spreading.

Patient: [takes a breath, possibly a gasp]

Oncologist: But none of them is more than 5 millimeters. What's going on in the liver. So, in the liver also there is the same thing. There is an increase in size and number of the [lymph nodes in the] liver. There is some fluid around your liver. Also in some area between -- the liver is covered by a capsule and there is some bleeding underneath the capsule from the old tumor dying. So there is some collection of fluid there. So, remember when you had that one instance where you had a tumor and you had a lot of pain in that area?

Patient: Yes.

Oncologist: That could have triggered the tumor dying and bleeding and stretching the capsule could have triggered your pain. And since then you haven’t had any pain?

Patient: No.

Oncologist: So that probably is what happened that time when we -- when I first saw you and you ended up in the hospital afterwards. Now this is more pronounced so we can go back and say this is why you had the pain at the time. So, clearly the disease is growing and I don't want to go over each lesion because the. . . each lesion does not matter. The fact that the disease has increased in size and number tells me that we need to change course. You know, just the Gemcitabine alone might not be enough…

Agentic Interaction Pattern

In 20 of the healthcare encounters, an interaction pattern occurred that we have labeled as agentic interactions. Agentic interactions are those in which patients and/or caregivers were particularly vocal during discussions with providers and/or very involved in making treatment decisions. In some of these interactions, patients or caregivers seemed to experience some urgency to relay information to providers. Sometimes patients or caregivers came prepared with lists of questions or topics they wanted to discuss or used notes or journals as prompts to ensure their concerns were discussed. For example, one caregiver mentioned to the provider several times that she “wrote my notes” and asked if she could read them. In other cases, patients or caregivers clearly stated what they wished to discuss or repeated their concerns or remarks several times until their issues were acknowledged by the providers. Some caregivers actively advocated for the patients whereas other caregivers contradicted the patients. In one case, a patient denied that he was troubled by his fatigue whereas his wife voiced her concern to the provider that her husband “slept around the clock.” Providers were typically responsive to the patients or caregivers who took control of the discussions, although a few patients or caregivers apologized for “pushing” or “questioning” providers.

An example of an agentic interaction follows. In this interaction, a 67-year-old man and his daughter talked about the severe taste change that was of concern to them both:

> Patient: You know, I just got through discussing that. My appetite, I want to eat. The problem I have doctor, and . . . is. . . when I eat everything tastes bitter.
>
> Oncologist: I see.
>
> Patient: And it’s hard to eat. It’s hard - even when you want to eat it’s hard to sustain yourself when you’re trying to eat something and the food

doesn’t taste like food or you get that initial something sweet. And then, and on the back end as you swallow it or whatever, it’s bitter. So I'm constantly getting this food don’t taste like food, it’s this bitterness that’s going on.

Oncologist: Are there any foods that you still enjoy or is this something that’s everything?

Patient: It’s a lot of foods that I enjoy and those are the ones I go after.

Oncologist: I see.

Patient: But I still get this, like last night I had a little, I wanted to have a little piece of pizza, you know, just a taste of tomato sauce.

Oncologist: Yeah. [keyboarding]

Patient: And that kind of thing. And I couldn’t eat it. It was just bitter. Um. . . that’s a problem for me, one issue right now I don't know how to deal with.

Oncologist: Okay.

Patient: Because it’s like I know to eat, my family is constantly on me about eating. And I know what you told me what I should be trying to do is the small meals. Okay. So those -- it’s just the problem is when I do try to eat something it’s. . . it’s the taste. I don't have the taste that I would normally associate with those foods that I like. And so this is an issue.

Oncologist: And that’s probably the chemo.

Patient: Yeah. This is an issue. I don't really know how to get around it. My wife says eat anyway. And i said -

Caregiver: Well, it’s so bitter it’s disgusting.

Patient: And I said, baby, it’s hard to eat when. . . when. . . what you’re eating is either doesn’t have a taste that you normally associate it with so it’s not as desirable as before.

Checklist Interaction Pattern

In 16 of the healthcare encounters, an interaction pattern occurred that we have labeled as checklist interactions. Checklist interactions are interactions in which the providers asked a series of questions in rote fashion, as if they were “going down” a list. The providers typically dominated these discussions. The questions were often closed-ended and focused on the patients’ signs and symptoms, although in some cases the questions were focused on the patients’ medication regime. The patients typically responded with brief answers, and, at times, the providers asked new questions before the patients completely answered the prior ones. For example, in one instance, the patient began to respond to a question about appetite, and the provider moved on to another question about weight loss. Sometimes caregivers chimed in to convey additional information.

An example of a checklist interaction follows. In this interaction, the oncologist asked a series of questions when performing physical exam on a 59-year-old man while his wife was present:

Oncologist: Do you have an appetite?

Patient: No. I’m not hungry. I…

Oncologist: Stick out your tongue for me. Deep breaths. You were having regular bowel movements.

Patient: Yeah, like every other day, too.

Oncologist: Solid or loose?

Patient: I’d say . . . solid. Yeah, solid.

Oncologist: Pain here as I press?

Patient: [Non verbal reply.]

Oncologist: Fevers at all?

Patient: None.

Oncologist: Shaking, chills?

Patient: None. I think for the most…

Caregiver: So, he’s not on [Emend]…Is he? It seems like…

Patient: I think they give me that on at the…

Caregiver: Which they have different names. It could be.

Oncologist: You’re getting … a steroid. But you’re not getting Emend.

Cross-purpose Interaction Pattern

In 14 of the healthcare encounters, an interaction pattern occurred that we have labeled as cross-purpose interactions. Cross-purpose interactions are those in which the patients and/or caregivers and providers seemed to have differing agendas and failed to acknowledge the remarks of the other. Often the providers changed the focus of the discussion without attending to concerns expressed by the patients or caregivers. For example, one patient mentioned how his fatigue was negatively affecting the quality of his life and questioned the value of chemotherapy. His provider did not acknowledge his distress but rather stressed that his cancer was well-controlled and briefly assured her that the fatigue would eventually subside. Some of the concerns of the patients and caregivers that were disregarded by the providers were stated explicitly and repeatedly whereas other concerns, especially those related to emotional distress or vague discomforts, were conveyed indirectly. For example, when one patient lamented that it was hard to accept the news that her disease had progressed because she still felt good, the provider replied, “[There is] no reason to think that feeling good actually is a bad thing.” Another patient said, “It [chemotherapy] doesn’t really knock me out. It just makes. . . just. . . like I want to lay down but then I’m restless and I get up and I’ll lay down again.” To this his provider replied, “Let’s leave things [chemotherapy dose] as they are.” In some cases, the patients or caregivers did not acknowledge remarks made by the providers or changed topics. For example, when one provider asked about a patient’s diarrhea, the patient did not answer but talked instead about taking pancreatic enzymes and her blood pressure medicines.

An example of a cross-purpose interaction follows. In this interaction, a 73-year old patient, his wife, and the provider all seemed to have different agendas regarding addressing the patient’s symptoms.

Patient: Because if I was to poke right in here.

Oncologist: A huh?

Patient: It’s not a pain but it aches really hard.

Oncologist: Hard. So have you been able to eat much?

Patient: I don’t eat at all.

Caregiver: Well, he’s. . . he eats very little. For a while he was hardly eating. Luckily he will drink the Glucerna.

Oncologist: Okay.

Caregiver: He’ll drink that. And something like maybe oatmeal.

Oncologist: Um hmm, okay.

Patient: Cup of tea.

Oncologist: Right. And you just don’t have the appetite for it?

Caregiver: Definitely.

Patient: Don’t have any taste there.

Oncologist: We can control the pain because. . .

Empathic Interaction Pattern

In 12 of the healthcare encounters, an interaction pattern occurred that we have labeled as empathic interactions. Empathic interactions are those in which the providers showed, or attempted to show, that they understood and cared about the emotions or experiences of the patients and/or caregivers. These interactions often occurred when patients or caregivers expressed strong emotions or relayed upsetting experiences. For instance, one patient cried when she talked about the suffering of another patient with pancreatic cancer at the end of life. In response, her oncologist acknowledged her feelings; he stated, “I'm sorry to hear this…I know it’s difficult to see those cases that the end of life might be painful.” Sometimes providers acknowledged the difficulty of the patients’ treatment by saying they were “doing great” or that they were “tough.” Some providers provided brief empathic responses but then negated in some way the feelings expressed by patients and/or caregivers. For example, one patient appeared distressed after the provider reported that imaging had shown a growth in the patient’s tumors. Her oncologist empathically responded, “I see you are really distressed and I can understand.” When the patient stated that she was distressed because she felt so good, the oncologist remarked that the patient was “hopefully not as surprised” as she could have been had the provider not prepared her for this outcome. Sometimes the providers’ empathic responses did not seem to “hit the mark” in accurately reflecting the patients’ feelings. For example, when a caregiver talked about feeling powerless to manage her husband’s fatigue and eating problems, the provider replied, ”Yeah… we’re hopeful about the marker coming down. We’re doing everything we can.”

An example of an empathic interaction follows. In this interaction, a provider attempts to respond empathically to a 69-year-old patient who expressed distress over her hair loss from chemotherapy:

Patient: And. . . um. . . I just discovered, what, about 3 days ago, my hair.
Oncologist: This chemo started making your hair fall out?
Caregiver: Um hmm.
Patient: And I was very depressed.
Oncologist: I'm sorry.
Patient: I know it happens. It didn’t happen the first time, the first time I had chemo.
Oncologist: I know.
Patient: So, I figured, you know, well okay, I'm one of the ones that it’s not gonna happen to. But well, you know, this is a wig that I have on. My hair, starting from back here up to about right here is all gone.

Oncologist: I'm sorry, [Patient].

Patient: Yeah.

Oncologist: It’s hard to tell because you always look good and this wig is so much like your real hair that it’s very hard to tell. You know? And a lot of people, I know especially African Americans sometimes have all kinds of braids and they change their style so much that it’s hard to, for people that don’t know, to tell that this is all happening.

Patient: Yeah.

Oncologist: But I know you can tell and that must be upsetting and I'm sorry. So what to do, some of these chemos, the newer ones, they’re stronger, they’re better in some ways but then their side effects are also a little bit, you know, more. And as long as the other things that affect quality of life like, you know, eating and energy, you’re not too badly affected, most patients say okay, I can wear a wig for a while.

Patient: Right.

Oncologist: And it will grow back, you know, down the road if this chemo is not necessary because the cancer is all gone or it’s under control and we can take a break or something, then certainly the hair would come back. Hopefully. It does, it does. Everyone’s comes back. Of course it may look a little different. It might be curlier or straighter.

Admonishing Interaction Pattern

In 6 of the healthcare encounters, an interaction pattern occurred that we have labeled as admonishing interactions. Admonishing interactions are those in which providers cautioned patients and caregivers against behaviors thought not to be in the patients' best interest or gently scolded them for taking certain actions or voicing certain opinions. When a caregiver mentioned that she thought the infection was a side effect of chemotherapy, the provider replied, "Just because you say it is doesn't mean that it was." In some cases, providers chided patients for not listening to them or failing to understand something the providers had said. For example, when a 76-year-old man said that his provider had not discussed surgery as a treatment option, the provider said this was "not true." The provider said, "[What] I'm giving you is clearly across the board [the] standard of care." When the patient mentioned seeking a second opinion, the provider replied, "I don't care where you go, who[ever] says it's standard of care to cut this out is not telling you the truth." In this interaction pattern, patients or caregivers often agreed with the providers or responded in a deferent manner. For example, one patient took antibiotics for urinary tract infection without notifying the provider. The provider instructed the patient to call him when the patient had symptoms rather than taking antibiotics. To this the patient responded, "I promise I won't do it again." In other cases, patients and/or caregivers resisted the providers' admonishments. For example, when one provider disapproved of the patient cutting back on his pain medicine, the caregiver said, "You said to use it, on my notes, use it as needed."

An example of an admonishing interaction follows. In this interaction, the provider, an 80-year-old patient, and her son discussed the patient driving while taking pain medication:

Oncologist: Had you just. . . are you careful about when you take your pain medicine and driving?

Patient: Well, I was. . . I find myself weaving sometimes and. . . I don't like to drive with a lot of people because they tend to weave. Do you know what I mean?

Oncologist: Well, you’re not filling me with a lot of confidence here.

Patient: [Chuckles] No, I don’t. . . like I knew I didn’t feel good Sunday. I never left my blankie…

Caregiver: But it’s not a frequent occurrence when you’re driving.

Patient: Oh, no, it was happening on Easter…when I was going to [name of relative]. So… I got off on the wrong place, and I wound up on those 3 roundabouts…Have you ever been on roundabouts…?

Oncologist: I know what you mean, yeah…Well, that is a little scary…So how much driving are you doing since then?

Patient: Oh, I drive, like to mah jong a couple of days a week and. . .

Oncologist: Is that like a few blocks or is that halfway across the city?...What do you do that for?

Patient: [Makes a fun noise]: Pow! [Chuckles] Slots.

Oncologist: Do you have a friend that can go with you?

Patient: Why? I have to take my car.

Oncologist: I don't like this, what you’re telling me about your driving, that’s why.

Patient: Oh. Well, basically I don’t drive on the days that I’m really feeling blech. I know when to drive…And the people that want to pick me up, like my sister, believe me, I’m better off driving. [Chuckles] She’s 85 years old and I think she’s beginning to get a little flaky.

Oncologist: Yeah, but she’s not on pain medicine. That’s what I’m concerned about.

Patient: I never feel tired from it…I mean I go to bed at 2 o’clock in the morning.

Oncologist: Well, I understand but it’s like alcohol. You don’t have to be falling down drunk to have decreased reflexes and maybe that’s why you were weaving a little bit.

Patient: … I said my driving days are numbered if I feel like I did today…I’m not dumb.

Oncologist: You’ve heard me and I know you’re not dumb. So.

Diverging Interaction Pattern

In 4 of the healthcare encounters, an interaction pattern occurred that we have labeled as diverging interactions. Diverging interactions are those in which providers and patients and/or caregivers expressed a disagreement. Some of the disagreements were related to the meaning or importance of the patients’ symptoms. For example, when a patient stated that he ate less because he felt full easily, his provider replied, “But you used to eat until you got full, right...So what’s the difference?” Others were related to treatment decisions. For example, while a patient and his caregiver requested surgery, the provider said that he’s “not a fan” of surgery. Some of these interactions seemed tense. For example, when a provider stated that it was “unusual” to expect a life expectancy longer than a year given the patient’s disease progression, the caregiver said, “Why? His case was unusual.” When the provider supported his argument with grim statistics, the patient replied, “I’ll be a statistic [exception].”

An example of a diverging interaction follows. In this interaction, the 76-year-old man, his wife, and the provider had different opinions about the cause of the patient’s pneumonia. Later, the patient also argued that he received different information from providers in the same facility.

Oncologist: That could have been a different virus that led to your decreased immunity that led to your pneumonia, actually. That’s probably the most likely thing.

Caregiver: But generally that kind of stuff starts getting better after 3 or 4 days.

Oncologist: Yes.

Caregiver: If it’s a virus.

Oncologist: Right.

Caregiver: And this wasn’t getting better.

Oncologist: Right.

Caregiver: And that’s when we called, it had been like the fourth or fifth day. And by the time he [another provider] could see us it was 7 days.

Oncologist: I'll bet you anything it was a virus. You didn’t think it was getting better because you got a subsequent pneumonia after the virus happened. And that’s called a secondary super infection. That actually happens a lot. I. . . I personally think it came about because of an initial virus more than anything and I, personally myself don’t think this has anything to do with the Everolimus. But prove me wrong -- I hope you don’t because I don't want you to have anymore infections.

Caregiver: We don’t want to prove you wrong.

Oncologist: I really do think you are tolerating very well. I see no reason to lower the dose. It’s doing what we asked it to do…I'm not pushing surgery by any means but if it’s something that you guys want to talk about then you guys should get together and talk about it.

Patient: Thank you. We’ve been bothered all along about the. . . we saw Dr. [Name] first and then you.

Oncologist: Sure, sure, sure.

Patient: A couple of times. And we saw him again, gosh, it must have been August or so.

Oncologist: Right.

Caregiver: July.

Patient: And we’ve seen you a couple of times since. And it just didn’t seem like there was, you know, we came into this thing thinking you guys were a team. And we didn’t feel that this team thing was a reality. That you had one. . . set. You know, you were definite on keeping me on this for ten years if it continued to work -

Discussion

The findings of this study describe how patients with APC, their caregivers, and healthcare providers interacted when discussing symptoms or symptom management during naturally occurring healthcare encounters. We identified eight unique interaction patterns: collaborative interactions, explanatory interactions, agentic interactions, checklist interactions, cross-purpose interactions, empathic interactions, admonishing interactions, and diverging interactions. Each interaction pattern varied according to the communication behaviors of each participant, how the interactions flowed, and which participant dominated the interactions.

Our findings can be interpreted according to the Dual Process Theory of Supportive Message Outcomes.[4-11] Specifically, two main constructs from the Dual Process Theory resonate with the interactions patterns identified in this study: verbal person centeredness (VPC) and patient and/or caregiver participation.

Verbal Person Centeredness (VPC)

According to the Dual Process Theory, VPC is "the extent to which messages explicitly acknowledge, elaborate, legitimize, and contextualize the feelings and perspective of a distressed other."[4-22] Messages with high VPC help message recipients describe their feelings and explore the meaning of those feelings in the context of the recipients' life situations.[4-23] VPC is evident in patient-centered communication in which a provider elicits, shows understanding of, or validates a patient's perspective.[7] Provider behaviors associated with VPC include avoiding interruptions, establishing the purpose of the visit, encouraging patient participation, eliciting and validating the patient's emotions, checking for patient understanding, and offering encouragement and support. [4-7] Patient-centered communication has been long advocated by healthcare experts. [4-7, 4-24]

In our findings, high VPC was particularly evident in the pattern of collaborative interactions. In this pattern, providers often acknowledged patients' concerns, used open-ended questions, and sought the perspectives of patients and/or caregivers in making treatment decisions. High VPC was also apparent in the pattern of empathic interactions. As found in other studies, [4-25] an important component of the healthcare encounters in our study involved providers expressing empathy by addressing patients' and/or caregivers' distressing emotions and acknowledging their adverse situations associated with their APC and its treatment. Such provider communication has been shown to have therapeutic value and positive effects on health outcomes such as higher medication-related self-efficacy. [4-25-4-27]

In contrast, low VPC was manifest in the patterns of checklist, cross-purpose, admonishing, and diverging interactions. In these interactions, providers did not acknowledge patients' and/or caregivers' perspectives but instead asked a series of questions without much input from them (checklist interactions), carried on discussions without realizing they had a different agenda (cross-purpose), scolded them for some of their thoughts or actions (admonishing interactions), and openly disagreed with their points of view (diverging interactions). Other studies have shown that provider communications that are not patient-centered can negatively affect patient outcomes by leading to low compliance with, passive participation in, or dissatisfaction with care. [4-15, 4-16, 4-25, 4-28]

Level of Participation

Patient and/or caregiver level of participation is the extent to which they are motivated, ask questions, present and process information, express concerns, and state their preferences during their healthcare encounters.[4-29] A high level of patient and/or caregiver participation was most evident in the pattern of agentic interactions. In this interaction pattern, patients and/or caregivers were particularly active in the encounters and often dominated discussions by expressing their needs, reporting information they deemed important, and getting their questions answered.

The levels of participation varied in the pattern of explanatory interactions. In several instances, patients did not actively respond to the information given to them or ask questions about it, despite that some of the information was related to the patients' poor prognosis. In other cases, explanations given by providers about test results or disease progression actually prompted patients and caregivers to become actively involved in the discussions as they responded to the information by asking critical questions about life expectancy and treatment options. Often provider explanations triggered meaningful end-of-life discussions.

Not surprisingly, some patterns of interactions that were low in VPC were also low in patient and/or caregiver participation. In particular, patient and/or caregiver participation in check-list and admonishing interactions was typically low. However, patients and/or caregivers could have high levels of participation in the patterns of cross-purpose and diverging interactions.

The results of our study are thus consistent with current communication theories and other research studies of patient-provider communication. However, while most studies have measured specific communication behaviors (e.g., asking questions) [4-29, 4-30] and factors that influence communication (e.g., beliefs about control and perceived quality of care),[4-31] our findings add to the literature by providing a qualitatively derived typology of interaction patterns based on naturally occurring healthcare encounters and robust exemplars of each type of interaction.

Limitations

Our findings should be understood in the context of the study limitations. The major limitation is that we used transcripts of healthcare encounters that had been established for a larger study designed to test a communication intervention. We therefore were able to analyze only the verbal communication that occurred in the encounters but did not have information about non-verbal behaviors. In addition, we analyzed transcripts of only one encounter and thus we were not able to explore how the interaction patterns may vary across time as the patient/provider relationships evolve.

Practice Implications

Despite these limitations, our findings have several implications for healthcare providers. The typology of interaction patterns might serve as a useful heuristic by which providers can reflect on their own interactions with patients and/or caregivers in efforts to improve communication. For example, the typology may serve as a springboard for discussions of strategies to facilitate interactions patterns likely to be associated with better communication (e.g., empathic interactions) or to increase provider awareness of patterns that may impede effective communication (e.g., cross-purpose or diverging interactions).

Future Studies

Although this study provides a basic description of a variety of types of interaction patterns, future research would be needed to validate and perhaps expand the typology. We recommend longitudinal studies that could capture how interaction patterns might change over time and would allow for researchers to conduct follow-up interviews with patients, caregivers, and providers about how they experienced the encounters and what might have influenced their behaviors during the encounters. Such studies would provide a more robust and dynamic model of interaction patterns. Ultimately studies would be needed to examine the relationship between interaction patterns, factors that influence those patterns, and patient outcomes, such as symptom management and satisfaction.

Conclusion

To our knowledge, this is the first study to examine naturally occurring patient/caregiver-provider symptom discussions in healthcare encounters for patients with APC. The typology of interaction patterns that we identified reflects the unique and varied ways that discussions related to symptoms and symptom management in this population can unfold. Although we recognize that more research is needed to validate the typology and to explore how the patterns are related to patient outcomes, the typology can be used to initiate conversations about how communication between patients/ caregivers and providers can be enhanced.

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CHAPTER FIVE

Managing symptoms effectively is imperative for patients living with APC due to their limited life expectancy, complicated treatment regimes, rapid physical deterioration, and the debilitating nature of some of the symptoms,[5-1, 5-2] Yet patients with APC often experience severe and poorly controlled symptoms that negatively affect their physical functioning, quality of life, and decision-making at end of life. [5-3-5-6] Communication about symptoms with providers plays an important role in symptom management. [5-3] Due to the importance of high quality symptom management in this population, more information is needed about the symptom experiences of patients with APC and about how communication about these symptoms occurs during healthcare encounters with providers.

The purpose of this dissertation is to advance the sciences of nursing, symptom management, and patient/caregiver and provider communication in patients with APC. The aims of this dissertation are to (1) synthesize current evidence regarding APC patients' symptom experiences, (2) examine recorded healthcare encounters between patients with APC, their caregivers, and healthcare providers to better understand the symptom experience of patients with APC as told to their healthcare providers, and (3) develop a typology to describe patterns of interactions between patients with APC, their caregivers, and healthcare providers in regards to symptoms and symptom management.

The findings of the dissertation will be disseminated in three sub-studies. Sub-study 1 (Chapter 2) addresses Aim 1; Sub-study 2 (Chapter 3) addresses Aim 2; and Sub-study 3 (Chapter 4) addresses Aim 3. The key findings from the three sub-studies, the strengths and limitations of the studies, recommendations for future research, and the clinical implications of the findings are discussed below.

Sub-study 1 (Chapter 2): The Symptom Experience of Patients with Advanced Pancreatic Cancer: An Integrative Review

Because research related to the symptom experiences of patients with APC had not been adequately synthesized, an integrative review of this research was conducted using Whittemore and Knafl's approach.[5-7] We searched and selected literature from four healthcare databases based on pre-determined inclusion and exclusion criteria. A total of 16 quantitative studies that included over 1630 pancreatic patients were included in this review.

Three major findings emerged from this integrative review. First, physical symptoms, especially pain, were the primary focus of most studies, with only approximately half of the studies discussing psychological symptoms. Second, fatigue, loss of appetite, and pain were the symptoms most often reported, and these symptoms were often reported as severe. Third, this research has been limited by designs that do not cover the full range of possible symptoms and that use a variety of different symptom measures, therefore making comparisons across studies difficult. Results of this integrative review inform both clinical practice and future research by identifying problematic symptoms that may have a profound effect on APC and their caregivers. In addition, this review identified limitations of previous research and supported the need for qualitative research to deepen our understanding of the symptom experiences of patients with APC.

Sub-study 2 (Chapter 3): Symptom Experiences in Patients with Advanced Pancreatic Cancer as Reported During Healthcare Encounters

Although several studies have measured the occurrence and severity of symptoms in patients with APC, [5-2] little is known about how patients and caregivers experience these symptoms and how the symptoms affect the quality of their lives. A qualitative descriptive study was therefore conducted to describe how patients with APC and their caregivers discussed symptoms with their providers during naturally occurring healthcare encounters. A total of 37 transcripts drawn from a larger randomized trial of a communication intervention were analyzed using standard content analysis.

Four major findings emerged in this study. First, patients and caregivers primarily discussed the following ten types of symptoms: pain, fatigue, abnormal bowel movements, decreased appetite, nausea and vomiting, sleeping problems, neurological problems, skin problems, taste changes, and psychological distress. Some of these symptoms were described as intense or highly distressing. Second, patients and caregivers discussed a range of factors they believed contributed to patients' symptoms, especially the progression of the cancer and the effects of chemotherapy. Third, patients and caregivers revealed that patients' symptoms often impaired the quality of their lives, caused psychological distress, and impaired their cognitive functioning. Fourth, patients and caregivers mentioned a variety of strategies that were used to manage symptoms, including taking medications for pain, changing eating habits for appetite change and nausea, and exercising to combat fatigue. Findings from this qualitative descriptive study support and extend existing evidence and provide a more nuanced understanding regarding symptom experiences from patients' and caregivers' perspectives. The findings indicate that providers should inquire about a wide range of symptoms and encourage patients and caregivers to discuss how they try to manage the symptoms and how the symptoms impact their day-to-day lives.

Sub-study 3 (Chapter 4): Patterns of Interactions Among Patients with Advanced Pancreatic Cancer, Their Caregivers, and Healthcare Providers During Symptom Discussions

Because few studies have been conducted that examine interactions between patients with APC, their caregivers, and their providers, this study used thematic analysis to develop a typology to describe patterns of interactions in regards to symptoms and symptom management. The 37 transcripts from the larger randomized intervention study mentioned above were analyzed for this purpose.

Eight patient/caregiver-provider interaction patterns were identified: collaborative interactions, explanatory interactions, agentic interactions, checklist interactions, cross-purpose interactions, empathic interactions, admonishing interactions, and diverging interactions. These interaction patterns varied according to the communication behaviors of each participant, how the interactions flowed, and which participant dominated the interactions. The results especially resonated with the Dual Process Theory of Supportive Message Outcomes. [5-8] With further validation, the typology can be used in provider and patient educational programs as a springboard for discussion of interaction patterns that facilitate or hinder patient-centered communication regarding symptoms and symptom management.

Summary

The findings of all three studies reveal that patients with APC experience a myriad of symptoms that are of great concern to them and their caregivers. In many cases, patients experience severe symptoms and the symptoms can significantly affect the quality of their lives and the lives of their caregivers. Psychological as well as physical symptoms can be troubling. The ways in which symptom discussions unfold in healthcare encounters also vary considerably. Some interactions regarding symptom discussions can be patient-centered and facilitate symptom discussions, likely leading to better symptom management. Other interactions do not focus on the patients and/or caregivers concerns and thus could possibly interfere with symptom management. The findings of all three studies suggest that patients with APC and their caregivers need ample opportunities to describe their symptoms fully and to discuss the meaning the symptoms have for their quality of life and illness course.

Comparing findings between sub-study 1 and 2 allows us to do triangulation to provide deeper insight regarding symptom experience in APC population. While major symptoms, such as pain, fatigue, loss of appetite, and digestive symptoms were overlapped in both sub-study 1 and 2, some symptoms identified by sub-study 2 were seldom addressed by quantitative studies analyzed in sub-study 1 and vice versa (table 5-1). For example, some studies addressed respiratory symptoms and oral dryness which were infrequently mentioned by our patients and caregivers during health encounters. On the other hand, our patients and caregivers described significant taste change, skin problems, and neurological problems which received little attention in most quantitative studies. Moreover, our patients described their neurological problems in different ways (e.g., neuropathy, abnormal sensation, tingling or numbness) while sub-study 1 shows that only one instrument measures numbness and no instrument addresses other neurological problems. In terms of psychological symptoms, most quantitative studies included in sub-study 1 focused on depression and anxiety while our patients and caregivers discussed a wide range of their psychological distress. Our findings of sub-study 2 also demonstrate patients and caregivers' experience and concerns regarding quality and distress dimensions of symptoms which were not the focus of the quantitative studies.

Innovation and Strengths

This dissertation was innovative in several ways. First, to our knowledge, it was the first study to synthesize current evidence regarding the symptom experiences of patients with APC. Second, it was the first study to use a qualitative approach to explore the symptom experiences of patients with APC based on their own words and those of their caregivers. Third, it was one of the few studies to examine what naturally occurring healthcare encounters reveal about the symptom experiences of patients with APC. Fourth, following the emerging research trends, [5-9, 5-10] this study considered how the verbal behaviors of all parties in healthcare encounters – patients, caregivers and providers – contributed to interactions regarding symptom experiences. By using innovative strategies, this dissertation uncovered new and useful information that builds on existing evidence regarding the importance of patient/caregiver and provider communication to improve symptoms and quality of life of patients with APC.

Limitations

Findings of this dissertation must be examined in light of its limitations. The major limitation was that data were drawn from a larger intervention study that had produced the verbatim transcripts of the healthcare encounters. [5-11] Although these transcripts provided robust data to meet the study aims, they did not allow us explore the nonverbal communication that occurred during the encounters nor to explore issues with participants post-encounter, such as how they experienced the interactions overall, the rationale for some of their verbal communication, and concerns they might have wished to discuss but did not have the opportunity to do so. Another limitation was that the participants may have changed their behaviors or altered their communication patterns because they knew they were being recorded. The Hawthorne effect, in which participants may alter their behavior due to their awareness of being observed, may have been a factor in this research. [5-12] Although the sample size was limited by the constraints of the existing data set, the sample size was between the 20 and 30 participants, which is considered typical for qualitative studies. [5-13] The results of our study may not be fully transferred to non-white population as nearly 90% of our patients are white.

Clinical Implications

The findings of this research can be used in several ways. First, the findings presented in sub-study 1 and 2 can raise the awareness of providers about the wide range of symptoms experienced by patients with APC, the myriad ways in which they try to manage these symptoms, and how the symptoms can affect the quality of their lives. These findings suggest that providers should obtain symptom narratives from patients with APC and their caregivers to facilitate a patient-centered approach to symptom management. The typology of interaction patterns can be used to facilitate reflection and discussion by both providers and patients and/or caregivers about what type of communication facilitates important symptom discussions and therefore enhances symptom management. The results presented in all three sub-studies may be used to enhance provider training in caring for and communicating with patients with APC.

Recommendations for Future Research

Several recommendations for future research are proposed. Frist, longitudinal qualitative and quantitative studies that follow patients and caregivers over time are needed to understand how patients' symptom experiences and communication patterns with providers unfold from diagnosis to end-of-life. Second, more studies are needed to explore psychological symptoms as these symptoms were the least likely to be addressed in current literature, but which our findings suggest profoundly affect the lives of patients and caregivers. Third, future studies are needed to validate or expand the interaction typology so it may be used as a foundation to develop strategies to improve symptom discussions in healthcare encounters for this population.

Conclusion

To our knowledge, this dissertation was the first study to examine the symptom experiences of patients with APC in-depth and to explore the nature of interactions among patients with APC, their caregivers, and their provides regarding their symptom experiences. Our findings demonstrate that patients with APC and their families experienced multiple burdensome physical and psychological symptoms that negatively affects their lives. Our findings also revealed a variety of types of healthcare interaction patterns, some of which were patient-centered and some of which were not. The findings have a number of implications that can further work aimed at developing strategies to improve symptom management in this vulnerable population.

Table 5-1. Symptoms Identified by Reviewed Studies and Current study

		Bye	Labori	Braun	Gao	Larid	Allen	Moningi	Walter	Stefaniak	Crippa	Seicean	Reyes-Gibby	Romanus	Dobratz	Muller	Current study
Physical	Pain	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
	Loss of appetite	X	X	X	X	X	X						X				X
	Fatigue/ lack of energy	X	X	X	X	X	X		X	X		X	X				X
	Sleep			X	X	X	X					X	X				X
	Respiratory			X	X	X	X						X				
	Oral dryness	X	X										X				
	Test change	X															X
	Digestive[a]	X	X	X	X	X	X	X				X	X				X
	Numbness												X				X (neurological problems)
Psychological	Senses of well-being	X	X							X							
	Anxiety	X	X											X			X
	Depression/ sadness	X	X						X			X	X	X			X
	Emotional distress/ mood disturbance												X				X
	Life enjoyment											X					
	Fear of future health problems							X									

[a] Digestive symptoms includes nausea and vomiting, flatulence, altered bowel movement and indigestion

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Liu, Y., **Tang, C**., Hung, T., Tsai, P., & Lin, M. submitted to Worldview on Evidence-Based Nursing. The Efficacy of Metacognitive Training for Delusions in Patients with Schizophrenia: A Meta-Analysis of Randomized Controlled Trials.

Tang, C.*, Von Ah, D., & Fulton, J. (2017). The symptom experience of patients with advanced pancreatic cancer: An integrative review. Cancer Nursing. doi:10.1097/NCC.0000000000000463

Lin, M., Hsu, W., Huang, M., Su, Y., Crawford P. and **Tang, C.*** (2017). ‘I couldn’t even talk to the patient’: Barriers to communicating with cancer patients as perceived by nursing students. European Journal of Cancer Care.

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PRESENTATIONS

Peer Reviewed

Tang, C., Draucker, C., & Von Ah, D. (2017, June). The Experience and Communication of Symptoms in Advanced Pancreatic Cancer Patients and Their Caregivers. Paper presented at the Proceedings of the 15th COMET conference, Indianapolis, IN.

Tang, C., Lin, M., & Lee, A. (2017, May). Factors predicting emotional cue-responding behaviors of nurses in Taiwan: an observational study. 42th ONS congress, Denver, CO.

Tang, C., Shields, C. & Von Ah, D. (2016, May). How Did Advanced Pancreatic Cancer Patients and Caregivers Communicate Their Needs in the Unstructured Medical Encounter. 2016 IU Cancer Research Day, Indianapolis, IN.

Lin, M. & **Tang, C.** (2016, April). "I couldn't even talk to the patient": Perceived barriers to communicating with cancer patients among nursing students in Taiwan. 41th ONS congress, San Antonio, TX.

Lin, M., Lee, A. & **Tang, C.** (2016, January). The predictors of emotional-cue responding competence among nurses interacting with a simulated patient. 2016 Asia-Pacific Conference on Education, Society and Psychology, Seoul, Korea

Tang, C., Von Ah, D. & Fulton, J. (2016, March). The symptom experience of patients with advanced pancreatic cancer: An integrative review. 40th Annual Midwest Nursing Research Conference, Milwaukee, WI.

Tang, C. & Wocial, L. (2015, April). Improving Patient-Health Care Provider End-of-Life Communication Using Improvisational Theater Techniques: Outcome of a Workshop. 2015 IU Research Day, Indianapolis, IN.

Tang, C., Guilkey, R., Storey, S., Nielsen, A. & Von Ah, D. (2015, April). Impact of Depressive Symptoms and Fatigue on Quality of Life in Breast Cancer Survivors. Paper presented at the Processing of 39th Annual Midwest Nursing Research Conference, Indianapolis, IN.

Guilkey, R., Storey, S., **Tang, C.**, Nielsen, A., & Von Ah, D. (2015, April). Pain and Anxiety and Quality of Life in Breast Cancer Survivors. 39th Annual Midwest Nursing Research Conference, Indianapolis, IN.

Nielsen, A., Guilkey, R., Storey, S., **Tang, C.,** & Von Ah, D. (2015, April). Physical Activity Level and Symptoms after Diagnosis and Treatment for Breast Cancer. Paper presented at the Processing of 39th Annual Midwest Nursing Research Conference, Indianapolis, IN.

Tang, C. & Von Ah, D. (2014, May). Terminal pancreatic cancer patients' end of life experiences: an integrative literature review. Paper presented at the Proceedings of the 39th ONS congress, Anaheim, CA.

Tang, C. & Von Ah, D. (2014, May). Unbearable suffering: a concept analysis. Paper presented at the Proceedings of the RESPECT conference, Indianapolis, IN.

Tang, C. & Lin, M. (2010, July). The need of innovative internet-based continuing nursing education in Taiwan. Paper presented at the Proceedings of the 2010 Conference on Information Technology and Applications in Outlying Islands, Taiwan.

Invited

Tang, C., Shields, C. G., & Von Ah, D. (2016, Sep). How Did Advanced Pancreatic Cancer Patients and Caregivers Communicate Their Needs: a Pilot Study. Paper presented at the Sigma Theta Tau International Leadership Connection, Indianapolis, IN.

FUNDING

Year	**Grant/Fellowship**	**Funding Agency**	**Amount**
2017	Walther Cancer Foundation Dissertation Research Funds	Walther Cancer Foundation	1,317
2017	Graduate Travel Fellowship Grant	IU School of Nursing	1200
2015-2016	Richard and Kaye Woltman Graduate Fellowship in Health Care Communication	Rancho Santa Fe Foundation	5000
2013-2016	Behavioral Cooperative Oncology Group Pre-Doctoral fellow	Walther Cancer Institute	21,180/ year
2013-2016	Research incentive fellowship Block Grant	IU School of Nursing	10000/ year