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The Efficacy of Psychosocial Services in Comprehensive Cancer Care: A Program Evaluation

Nicola B. Mucci
Antioch University Seattle

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THE EFFICACY OF PSYCHOSOCIAL SERVICES IN COMPREHENSIVE CANCER CARE:
A PROGRAM EVALUATION

A Dissertation

Presented to the Faculty of
Antioch University Seattle
Seattle, WA

In Partial Fulfillment
of the Requirements of the Degree
Doctor of Psychology

By

Nicola B. Mucci

August 2016

THE EFFICACY OF PSYCHOSOCIAL SERVICES IN COMPREHENSIVE CANCER CARE:
A PROGRAM EVALUATION

This dissertation, by Nicola B. Mucci, has been approved by the committee members signed below who recommend that it be accepted by the faculty of the Antioch University Seattle at Seattle, WA in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

Dissertation Committee:

Jude Bergkamp, Psy.D.
Chairperson

Tricia Teneycke, Psy.D.

Kathryn Johnson, Ph.D.

Date

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ABSTRACT

THE EFFICACY OF PSYCHOSOCIAL SERVICES IN COMPREHENSIVE CANCER CARE:

A PROGRAM EVALUATION

Nicola B. Mucci

Antioch University Seattle

Seattle, WA

On average, regardless of other factors, persons affected by cancer will experience some level of distress associated with the disease and its sequelae. Left untreated, psychosocial problems can, and often do, adversely affect a person's health and healthcare treatment. As a result, national initiatives have been implemented to recognize and treat psychosocial stressors to optimize a person's functioning and facilitate successful movement through the medical system. A program evaluation was conducted to examine how Providence Regional Cancer Partnership has addressed the psychosocial needs of its patient population. Specifically, the psychosocial services department, Patient Support Services, was evaluated to understand how program services were (a) utilized and represented across patient demographics and (b) valued or regarded within the larger cancer treatment center. Archival data was gathered from electronic health records to determine how program services were utilized and by whom. Two surveys were designed and distributed to understand the experiences and opinions of program services. Evaluation findings clarified areas of strength and identified areas of improvement. Program strengths provided insight into services that were well utilized and most valued and affirm the program's mission to reach a broad patient population and provide services to patients in high need. Utilization of program services indicated two areas of underrepresentation (gender and cancer diversity) and one area of underutilization (support groups). Areas of program

dissatisfaction identified by patients and staff were categorized into three themes: education and outreach; program services and access; and Patient Support Services staffing. Recommendations were developed with input from Patient Support Services and presented to stakeholders and program administrators to make informed decisions about desired program changes. In general, evaluation findings provided efficacy of program services and support for the merit of psychosocial services within a cancer treatment facility. The electronic version of this dissertation is at AURA: Antioch University Repository and Archive, <http://aura.antioch.edu/> and OhioLINK ETD Center, <https://etd.ohiolink.edu>

For anyone who has ever been affected by cancer, but especially Kathy Mucci and Jerome Jimenez who both lost their lives to cancer while this dissertation was being finalized. Those affected by cancer, either directly or indirectly, know its effects are wide and harrowing on our minds, bodies, and souls. This dissertation is a reminder of the importance of tending to the psychosocial elements of the disease and its sequelae. May the merit of psychosocial factors be more fully realized and respected among our medical communities.

And to Daniel, your unwavering support and love has given me so much strength and humility. Thank you for being my greatest admirer and for encouraging my endeavors, despite the many sacrifices they required. You light up my life and have made this incredible feat feel a little easier and certainly more worthwhile.

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Chapter I: Background

In 2015, the National Comprehensive Cancer Network ([NCCN], 2016b) estimated 1,658,370 new cancer cases, with approximately 36%, or 589,430 , cancer-related deaths in the United States. Data available from the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) predicts that, per all incidences of cancer, men have a 42% lifetime risk of developing cancer while women have a 38% lifetime risk (American Cancer Society [ACS], 2016). Thus, nearly one half of all men and one third of all women in the United States will develop cancer in their lifetime.

Fortunately, despite a high prevalence of cancer among all Americans, substantial progress has been made in the field of oncology which has significantly extended the life expectancy of persons with cancer, with many people achieving remission or living with cancer as a chronic condition (ACS, 2016). Nevertheless, people with cancer face an array of physical, psychological, social, and economic hardships often as a result of a cancer diagnosis and its sequelae. And while advances in biomedical care have improved the early detection and treatment of many malignant tumors, similar recognition has not been paid to the necessity of high quality psychosocial care in addressing problems associated with cancer. Indeed, survivors of cancer and family members have reported a lack of understanding and/or failure to address important psychosocial needs by their cancer care providers (Institute of Medicine [IOM], 2008). In response to these concerns, national initiatives have been implemented over the years to recognize and treat psychosocial stressors to optimize the overall health of persons with cancer. New standards of care emphasize the inclusion of psychosocial services in delivering high quality cancer care because, as the sentiment of the World Health Organization expressed in

2001, without mental health, good health cannot exist. Left untreated, psychosocial problems can, and often do, adversely affect a person's health and healthcare treatment in many ways.

This dissertation outlines psychosocial stressors that commonly accompany a cancer diagnosis and the individual and systemic risks of not treating psychosocial concerns as an integral part of cancer care. A program evaluation was conducted to examine how one institution, Providence Regional Cancer Partnership, has addressed the psychosocial needs of its patient population. An internal behavioral health team known as Patient Support Services assesses distress, identifies psychosocial needs, and delivers a wide array of onsite program services to help patients manage distress and effectively cope with the rigors of cancer and its sequelae throughout all phases of the cancer continuum. A strength of the Cancer Partnership is its ability to provide a robust program of onsite psychosocial services that reaches far beyond distress screening required by governing oncology sanctions. This program evaluation sought to determine the overall merit of Patient Support Services and provide feedback to improve psychosocial program services as indicated by data on the utilization of services and patient and staff feedback.

Psychosocial Distress Among Cancer Patients

While advances in early detection and treatment of cancer have improved overall survival rates of patients with cancer, the effects of cancer and treatment often have long-lasting consequences that can interfere with a person's ability to function optimally, contributing to psychological distress. Distress is an all-encompassing term chosen by the NCCN (2016b) to describe the subjective experience of adversity and psychological hardship likely to accompany cancer. The term "distress" aims to normalize psychological hardship, rather than pathologize persons reacting to the wide-reaching affects of cancer. In 1999, the term was selected by an

interdisciplinary group to reduce the potential barrier between people in need of psychosocial services, but reluctant to label themselves as needing help, and the clinicians who provide services. Distress was defined globally as

A multifactorial unpleasant emotional experience of a psychological (i.e, cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (NCCN, 2016b, p. DIS-2)

While the prevalence of psychosocial distress varies based on individual demographics (i.e., age, gender, race, marital status, income) as well as type and stage of cancer, research suggests that one third of patients newly diagnosed with first time or recurrent cancer will experience a significant level of distress as they adapt to their diagnosis (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Zabora and colleagues examined psychological distress among 4,496 patients with cancer and found the overall prevalence rate of distress was 35.1%. Of 14 cancer diagnoses included in the study, those cancers with poorer prognostic rates and/or multi-modality treatments demonstrated greater rates of distress. Lung cancer patients were found to have the highest prevalence of distress (43.4%) followed by patients with brain, liver, pancreatic, and head and neck cancers, while gynecological cancer patients showed lower prevalence rates (29.6%).

On average, regardless of other factors, persons affected by cancer will experience some level of distress associated with their cancer diagnosis as well as the overall effects of the disease and/or related treatments. Indeed, symptoms of psychological distress are expected and mild

symptoms can be deemed an appropriate, “normal” response to enormity of the disease and rigors of treatment. Helgson and Cohen (1996, as cited in IOM, 2008) defined psychological adjustment as an “adaption to disease without continued elevations of psychological distress (e.g, anxiety, depression) and loss of role function (i.e., social, sexual, vocational)” (p. 54). Even with the most robust resources available to a person, cancer will disrupt all aspects of a person’s daily life including relationships, employment, and finances (Zabora et al., 2001). The most commonly reported effects of cancer depict both physiological—fatigue and pain—and emotional— anxiety and depression—symptoms as patients confront their illness and the numerous cancer-related decisions that face them. Other symptoms of expected distress include feelings of uncertainty and fear about the future or feeling out of control; anger, irritability, and grief as one’s health and functioning changes; thoughts of morbidity and mortality; sleeplessness, changes in appetite and concentration, concerns about the illness and a preoccupation with side effects from treatment; and concerns about one’s identity and social roles (NCCN, 2016b). Most patients will experience signs of distress during pivotal moments, for instance while facing a potential diagnosis of cancer, throughout arduous phases of treatment, and following the completion of treatment.

While psychosocial distress is expected even among psychologically healthy persons, persons with preexisting psychiatric disorders represent a more vulnerable population of cancer patients who may have greater difficulty coping with the disease (NCCN, 2016b). Patients bring with them a multitude of characteristics and psychosocial factors and, not surprisingly, those variables can either add to patients’ resiliency— nearly two-thirds of patients successfully adapt to their cancer diagnosis without clinical intervention— or hinder their ability to adapt to their cancer experience, the remaining one third demonstrated by Zabora et al. (2001). Research conducted as far back as the 1980s (Wesiman, Worden, & Sobel, 1980, as cited in Zabora et al.,

2001), demonstrated that preexisting psychosocial factors, including social support and previous history of functioning, significantly contributed to a person's initial adaption to cancer. With psychosocial variables in mind, providers may begin to identify persons at risk of experiencing greater difficulty and poor adjustment.

It is of the utmost importance to identify and treat the subset of patients likely to experience clinically significant levels of distress to optimize patients' successful movement through the medical system. Compared to patients with mild symptoms of distress, persons exhibiting symptoms of severe distress may show signs of excessive worry or fear; extreme sadness, feelings of despair or hopelessness; confused or unclear thinking; and severe problems involving their family, spirituality, or social concerns (NCCN, 2016b). Patients with a history of psychiatric illness, including substance abuse and cognitive disorders, are at greater risk of experiencing severe psychosocial distress. Other populations at risk of acute distress include persons with complex comorbid disorders or difficult to control symptoms and persons with an array of social issues such as limited social support, limited access to resources or fewer financial resources, conflict with family members or caregivers, communication barriers or cultural and spiritual/religious concerns. Patients may also be at greater risk of distress during periods of vulnerability throughout the course of treatment. Vulnerable periods may include initial workup prior to diagnosis, changes in treatment modalities, treatment resistance or failure, side effects or complications during treatment, treatment completion, disease progression or recurrence, and end of life (NCCN, 2016b). Clearly, many factors may complicate an already arduous experience for persons facing cancer, including a history of psychiatric illness, psychosocial issues, and treatment-related concerns or complications.

Consequences of Unmet Psychosocial Needs

Given the high prevalence of distress among cancer patients and implications for coping with the disease and rigors of treatment, the importance of addressing psychosocial distress cannot be understated. Indeed, a failure to identify and treat clinically significant levels of distress can have negative effects on an individual and organizational level. Many patients experience significant mental health problems that can impair quality of life and the ability to carry out social and functional roles. Ultimately, untreated psychosocial problems and distress can affect the onset and progression of disease interfering with treatment compliance, compromising treatment outcomes, and escalating healthcare costs (IOM, 2008).

Meta-analyses conducted by the National Comprehensive Cancer Network (2016b) and Institute of Medicine (2008), two of the leading international organizations responsible for creating oncology standards of care, have discussed the perils of unmet psychosocial needs and the affects on patients. In general, research has focused on three psychosocial variables proven to affect patient care and treatment outcomes: depression and mental health issues, inadequate social support, and insufficient finances or access to resources.

Emotional distress. All persons are at risk of emotional suffering when confronted with a potentially life-threatening disease such as cancer (NCCN, 2016b). People afflicted by depression or anxiety and comorbid health conditions tend to report more social and functional impairment than their non-depressed, non-anxious peers. Somatic symptoms that accompany emotional distress such as sleep issues, fatigue, and pain can exacerbate physical symptoms associated with cancer and treatment, leading to further functional impairment and greater difficulty engaging in change behaviors that promote health (IOM, 2008).

By and large, the most serious consequence of emotional distress on health is its interference with adaptive coping and adherence to treatment recommendations. Studies have indicated that as many as 20% of cancer patients have been noncompliant with treatment recommendations including oral chemotherapy, radiation, and adjuvant hormone therapy (IOM, 2008). Psychological distress can alter patients' perceptions and motivation to engage in healthy, adaptive coping skills. Self-defeating and pessimistic attitudes, for example, may contribute to feelings of helplessness and powerlessness that prevent patients from engaging in treatment-related decisions. Adaptive coping skills may be averted or delayed and patients may gravitate towards unhealthy or avoidant behaviors—smoking, excessive alcohol use, medication misuse—in an effort to cope with emotional distress. Avoidant-based coping, in particular, has harmful consequences on treatment adherence as patients disengage from the problem-solving skills and decision-making (IOM, 2008).

Depression and other psychological disorders can also impair cognition including thought processes, perceptions, memory, and executive functioning skills (American Psychiatric Association, 2013). Thus, stress, anxiety, and depression among cancer patients can affect the ability to adequately process complicated information necessary to understand the disease and treatment options. Distraught patients may struggle to work effectively with their treatment providers or participate in making treatment decisions leading to poorer outcomes (IOM, 2008).

Inadequate social support. Social support plays a pivotal role in helping persons with cancer manage their illness and shield them from the array of stressors involved. Social support can improve healthcare outcomes by helping patients cope with the emotional stress of illness and the rigors of treatment procedures, providing informational support during instrumental treatment phases, and/or logistical support as a person's functional abilities and roles change

throughout the course of illness and treatment. With the knowledge that social support can help mitigate the stressors related to the challenges of illness, it is not surprising that inadequate or dysfunctional support systems can negatively affect the course of illness, including worse treatment outcomes and higher mortality rates (IOM, 2008). Inadequate social relationships lead to a decreased ability to cope with illness and often increase stress rather than insulate a person from it.

Insufficient financial and material resources. Persons with fewer financial resources are also at greater risk of developing severe distress. Limited access to resources or financial means can interfere with a person's ability to fully participate in healthcare, thereby inadequately managing his/her illness. Indeed, a survey conducted in 2006 on households that were affected by cancer found that 8% of families had delayed or declined treatment because of the cost of care (IOM, 2008). Given the necessity of wealth and access to resources in this country, especially in the management of disease and health maintenance, socioeconomic status has become a strong predictor of illness, disability, and mortality rates (IOM, 2008).

In general, psychosocial stressors such as those described above—depression and mental health problems, inadequate social support, and insufficient financial resources—are correlated with higher morbidity and mortality rates as well as lower functional status (IOM, 2008). In and of itself, psychological distress can cause emotional suffering and significantly decrease a person's effectiveness in his/her social and economic roles. Furthermore, psychosocial problems can affect health by obstructing a person's ability to effectively manage his/her illness, thereby creating suboptimal conditions for treatment. Studies have shown that psychosocial problems can impede access to necessary healthcare and treatment resources, interfere with treatment

compliance, and restrict engagement in adaptive behaviors that promote good health (IOM, 2008).

In summary, persons with cancer must approach their cancer treatment from two angles: First, they must face their illness and the risks to their physical health that are at stake. Secondly, they must confront the many psychosocial challenges related to the sequelae of cancer that threaten optimal functioning and high quality healthcare. As Zabora and colleagues indicated in their 2001 review of the prevalence of psychological distress among cancer patients, “Failure to detect and treat elevated levels of distress jeopardizes the outcomes of cancer therapies, decreases patients’ quality of life and increases healthcare costs” (p. 27). Thus, the detection and treatment of clinically significant levels of distress is critical in providing comprehensive cancer treatment.

Early psychological intervention in particular, can benefit both patients and the medical institution. While psychological interventions may not affect cancer cure rates, evidence supports its efficacy helping patients adopt positive coping mechanisms that can minimize symptoms of physical and psychological distress and improve overall health (IOM, 2008). In general, patients who receive psychosocial services have better quality of living and a lower likelihood of developing severe emotional disorders (NCCN, 2016b). Additionally, these patients report greater satisfaction in their cancer care. Systemically, psychological interventions during appropriate treatment intervals help patients optimize their healthcare experience; psychosocial interventions are expected to improve treatment compliance and provider recommendations, reduce unnecessary office visits with physicians and emergency room resources, and increase communication and collaboration with providers (NCCN, 2016b). Further, psychosocial services within oncology aim to benefit the community by promoting better health and wellness and

working to improve the delivery of services and care for all persons affected by cancer (Association of Oncology Social Work [AOSW], 2012).

Psychosocial Standards of Care and Distress Management

The National Comprehensive Cancer Network (2016a), an alliance of the world's most premier cancer centers, is collectively responsible for the development of standards and clinical practice guidelines affecting patient care, research, and education. NCCN creates resources that lead cancer institutions in delivering high quality cancer care, including the identification and treatment of psychosocial services in patients with cancer. Indeed, since 1997, NCCN (2016b) has sought to create provisions to advocate for and improve psychosocial care in oncology settings. The first clinical practice guidelines on the management and treatment of distress were published in 1999 by a panel of interdisciplinary specialists. Since its inception, these guidelines have provided a framework for understanding psychosocial distress and they continue to inform all future handbooks for oncology specialists and clinicians.

In 2008, the Institute of Medicine issued the first report recommending the inclusion of psychosocial distress screening and appropriate treatment, creating a new standard of quality cancer care. IOM standards provided recommendations for the effective delivery of psychosocial health services within oncology settings. The proposed model of care begins with effective communication between patients and their providers to screen and detect psychosocial needs. Once needs are identified, providers are encouraged to connect patients and families to resources and support, which may include internal or external services. A strength in this approach is its reliance on the use of interdisciplinary collaboration to coordinate psychosocial and biomedical care. Figure 1 provides an illustration of the cyclical model proposed by IOM (2008, p. 8).

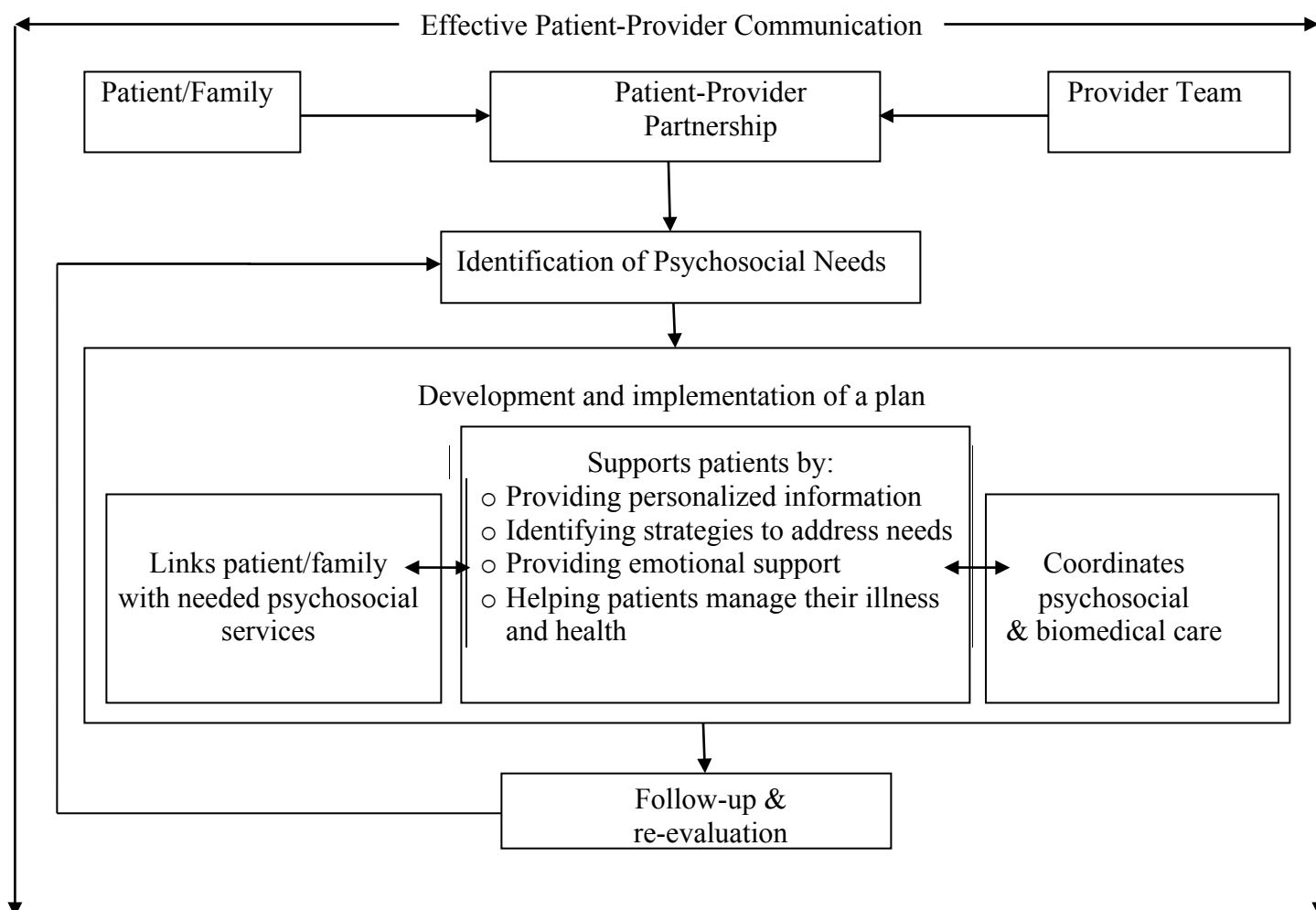


Figure 1. Model for the delivery of psychosocial health services. Reprinted with permission from *Cancer Care for the Whole Patient*, 2008 by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, D.C.

Standards of practice for oncology social workers, the primary professional discipline responsible for providing psychosocial services in cancer settings, expands upon IOM recommendations to provide more detail regarding the role of clinicians delivering psychosocial services. The Association of Oncology Social Work (2012) recommends clinical providers possess knowledge of oncological disease and associated treatments to understand the psychosocial implications for patients and family and appropriately support them in coping with anticipated challenges and changes that occur. Clinicians are encouraged to explore patients'

understanding of their disease, reactions, and expectations while also assessing the psychosocial functioning of the patient and family including strengths, coping skills, socioeconomic resources, and cultural and spiritual factors that may affect oncology care. Clinical providers are tasked with identifying patients at high risk of suboptimal psychosocial functioning during their treatment. Similarities can be seen in the recommendations proposed by AOSW in 2012 and the psychosocial factors outlined by Wesiman, Worden, and Sobel in 1980 (as cited in Zabora et al., 2001), demonstrating the resoluteness of psychosocial variables affecting healthy adaptation to disease.

Implementation of standards and guidelines. In 2012, new accreditation standards for cancer treatment centers were released by the Commission on Cancer of the American College of Surgeons (ACoS); whereas previous standards were once recommendations, new accreditation standards required all patients receive screening for psychosocial distress as part of routine care (NCCN, 2016b). These most recent standards were subsequently endorsed by the American Psychosocial Oncology Society (APOS), the Association of Oncology Social Work (AOSW), and the Oncology Nursing Society (ONS).

NCCN (2016b) guidelines for the management of distress were intended to assist oncology teams in identifying cancer patients with distress and/or psychosocial needs and recommending appropriate treatment interventions. According to the established standards of care, distress should be assessed, documented, and promptly treated at all stages of a patient's disease and throughout appropriate treatment intervals. The detection of distress begins with a brief screening tool to identify distress levels (e.g., mild, moderate, severe) and specific areas of distress (e.g., practical concerns, family problems, emotional difficulties, spiritual or religious

concerns, physical problems, etc.). The reader may refer to Appendix A to review NCCN (2016b) standards of care for distress management.

Subsequently, the NCCN (2016b) created the Distress Thermometer (DT) to quickly identify sources of distress related to cancer. A standard, brief questionnaire format was used to identify distress and psychosocial needs and assist in developing a plan to manage needs. While screening is a critical component of psychosocial care, the DT was, more importantly, designed to facilitate dialogue between providers and patients and to ensure that psychosocial needs do not go unrecognized and untreated in busy ambulatory care settings. The oncology team is often the first to detect psychosocial concerns and, thus, providers must handle these conversations with compassion and sensitivity:

It is important for the oncology team to acknowledge and validate that this is a difficult experience for the patient and that distress is normal and expected. Being able to express distress to the staff helps provide relief to the patient and builds trust. (NCCN, 2016b, p. MS-12)

Once psychosocial needs are identified, patients need access to appropriate referral sources and treatment. Cancer patients are not a homogenous group with homogenous needs; interventions must to be selected according to where patients are on the continuum of distress and cancer-related needs. NCCN recommends psychological interventions that offer psychoeducation, resources that promote medication management and healthy lifestyle choices, counseling, relaxation strategies, and spiritual support. Additionally, psychosocial providers should be prepared to assess patients' capacity to make treatment decisions and concerns related to safety. Table 1 outlines examples of psychosocial needs and corresponding services to treat specific areas of distress, as proposed by IOM (2008).

Table 1

Psychosocial Needs and Formal Services to Address Them

Psychosocial Need	Health Services
Information about illness, treatments, health, and services	<ul style="list-style-type: none"> • Provision of information, e.g., on illness, treatments, effects on health, and psychosocial services, and help to patients/families in understanding and using the information
Help coping with emotions and accompanying illness and treatment	<ul style="list-style-type: none"> • Peer support programs • Counseling/psychotherapy to individuals or groups • Pharmacological management of mental symptoms
Help in managing illness	<ul style="list-style-type: none"> • Comprehensive illness self-management/self-care programs
Assistance changing behaviors to minimize impact of disease	<ul style="list-style-type: none"> • Behavioral/health promotion interventions, such as: <ul style="list-style-type: none"> - Provider assessment/monitoring of health behaviors (e.g., smoking, exercise) - Brief physician counseling - Patient education, e.g., in cancer-related health risks and risk reduction measures
Material/logistical resources	<ul style="list-style-type: none"> • Provision of resources
Help in managing disruptions in work, school, and family life	<ul style="list-style-type: none"> • Family and caregiver information • Assistance with activities of daily living, chores • Legal protections and services, e.g., under Americans with Disabilities Act and Family and Medical Leave Act • Cognitive testing and education assistance
Financial advice and/or assistance	<ul style="list-style-type: none"> • Financial planning/counseling, including management of day-to-day activities such as bill paying • Insurance (e.g., health, disability) counseling • Eligibility assessment/counseling for other benefits (e.g., Supplemental Security Income, Social Security Disability Income) • Supplemental financial grants

Note. Care for the Whole Patient, 2008 by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, D. C.

Providence Regional Cancer Partnership

In 2007, Providence Regional Cancer Partnership (PRCP), also referred to as the Cancer Partnership throughout, was founded in collaboration with four of the region's leading healthcare organizations: Providence Everett Medical Center, The Everett Clinic, Western Washington Medical Group, and Northwest Washington Radiology Oncology Associates. PRCP was established with the intent of creating an integrative outpatient treatment center where all aspects of patient care could be provided in one building including: chemotherapy, radiation oncology, clinical research, and integrative medicine where behavioral health services reside. PRCP's vision statement conveys the standard of care they have strived to provide, "[PRCP is] a comprehensive, regional, state-of-the-art, single destination designed exclusively for the cancer patient and family with integrated and seamless clinical, operational and business processes" (PRCP, 2009, p. 1). An illustration of PRCP's organizational structure is found in Appendix B.

As of 2013, the Cancer Partnership was recognized as the fourth largest cancer program in the region based on the number of patients served annually (PRCP, 2015a). PRCP is accredited by the Commission on Cancer which ensures high-quality cancer care based on data-driven performance measures overseen by the American College of Surgeons (2014). Indeed, the Cancer Partnership recently achieved the Outstanding Achievement Award after attaining the Approval Award with Commendation for three consecutive years (PRCP, 2015a). Additionally, the Cancer Partnership is certified by the Quality Oncology Practice Initiative, a program administered by the American Society of Clinical Oncology to ensure high practice standards of quality and safety through ongoing assessment (ASCO, 2016). PRCP's adherence to these standards speaks to its culture of excellence and commitment to continued self-examination and improvement.

Patient population. PRCP treats a wide range of cancers and hematology disorders. The Cancer Partnership employs specialists in medical oncology, radiation oncology, surgical oncology, thoracic oncology, gynecologic oncology, and neurosurgery. The reader is encouraged to refer to Appendix C, which outlines the expansive list of medical and support services offered at PRCP during 2014.

During the 12 months this evaluation was conducted, PRCP saw 1904 new cancer cases, which is consistent with the average number of patients treated in previous years. Fifty-six percent of all new patients were female ($n = 1067$), while 44% were male ($n = 837$). The most frequently diagnosed tumor sites included breast ($n = 370$, 19.4%), lung ($n = 275$, 14.4%), prostate ($n = 105$, 5.5%), lymphoma ($n = 92$, 4.8%), bladder ($n = 92$, 4.8%), and uterine cancer ($n = 92$, 4.8%). Patients with stage I cancer were most prevalent among new cancer cases ($n = 561$, 29.5%), followed by stage IV ($n = 375$, 19.7%). PRCP's patient population is looked at more closely in the chapters that follow as this evaluation examined patient demographics and trends in utilization of psychosocial program services. The reader may also refer to Appendices D, E, and F for a comprehensive look at the patient population during the time of this evaluation, including the incidence of cancer site by gender, stage, and insurance type.

Psychosocial Services. As the Cancer Partnership was being conceptualized in 2005, a multidisciplinary task force was concurrently planning and developing the inclusion of psychosocial services, which became known as the department of Patient Support Services (PSS). The mission and goals of PSS were established in alignment with NCCN (2016b) clinical practice guidelines for the management of psychosocial distress. At the time, psychosocial support goals were identified as follows (PRCP, 2005a):

- To assess the psychosocial needs of each newly diagnosed patient

- To help patients and their families cope more effectively with the rigors of cancer treatment and follow-up
- To connect patients and family members with appropriate community resources to meet their needs
- To be available as a resource to help patients manage distress throughout their treatment
- To ensure that all patients, family members, and caregivers receive access to psychosocial services to support the best possible outcomes for persons affected by cancer

PSS has become an internal behavioral health team tasked with addressing the psychological and social distress likely to accompany cancer throughout all phases of the cancer continuum including diagnosis, treatment, survivorship, terminal care, and bereavement. The department's strength resides in its ability to offer patients and family members a wide range of support options, beyond distress screening required by governing oncology sanctions. While distress screening measures help monitor the psychological acuity and health of the patient population at PRCP, the department offers a multitude of support services and interventions to help patients utilize the healthcare system more effectively, mitigate psychosocial distress, foster positive coping strategies, and optimize functioning, as suggested by AOSW (2012) guidelines. In-house onsite psychosocial services reflect many of the services recommended by IOM (2008) and may include education and advocacy, crisis intervention, individual and family counseling, formal and informal assessments, support groups and group therapy, case management and community resourcing, and financial assistance. PSS works closely with integrative medicine to provide holistic healthcare and psychosocial support to patients, family members, and caregivers

five days a week. Many services are offered at no cost to patients or family members. The reader may refer to Appendix G to review a copy of PRCP's policy and procedure regarding access to psychosocial services. Additionally, Appendices H and I provide the full list with descriptions of support resources advertised at PRCP.

PSS strives to be an integral part of the interdisciplinary oncology team, contributing to the overall treatment of person's cancer. In 2015, psychosocial services were identified as an area of focus and growth by PRCP's clinical and administrative leaders with the goal of promoting integrative medicine and Patient Support Services, inside and outside the organization (PRCP, 2015a).

Distress management at PRCP. Since its inception, PRCP has been committed to following guidelines for distress management set forth by the NCCN (2016b) and IOM (2008). In compliance with standards, PRCP has implemented procedures for ascertaining cancer-related distress for medical and radiation oncology patients during appropriate treatment intervals. Psychosocial distress screening procedures are outlined as follows and a full copy of PRCP's policy and procedure can viewed as Appendix J (PRCP, 2012b).

Distress Assessment tool. PRCP uses a standard, paper-and-pencil patient questionnaire modeled after the NCCN (2016b) Distress Thermometer to routinely monitor psychosocial distress and assess the need for services. PRCP's Distress Assessment (DA) questionnaire asks patients to quantify their experience of distress during the past week. The term "distress" is intentionally undefined so patients may freely interpret their experience of distress, physical, emotional, or otherwise. Additionally, the DA inquires more specifically about several areas of distress including, practical concerns, emotional problems, family difficulties, and spiritual concerns. Patients may also request additional information about psychosocial resources (i.e.,

Medicaid, Medicare, Social Security) and PRCP support programs (i.e., nutrition, support groups, hospice care). Please refer to Appendix K to review a complete version of PRCP's DA questionnaire.

Procedures. All patients who receive treatment at PRCP are screened for distress throughout their care, however, distress screening procedures vary based on the treatment patients receive. Medical oncology patients receive a DA questionnaire on days they both meet with their oncologist and receive infusion treatment. DA questionnaires may also be provided during pivotal intervals of care such as treatment completion, disease remission, or disease progression. By contrast, radiation oncology patients meet with their oncologist much more frequently and, therefore, only receive a DA questionnaire the day of their intake appointment.

DA forms are generally screened on at least two occasions, first by a treatment provider so that distress can be addressed during a patient's office visit or treatment session, and second by PSS staff for further follow-up. PSS staff assesses DA forms to "determine if there are any psychological, behavioral, social, practical, financial, or spiritual problems that might interfere with the patient's ability to participate fully in their healthcare and adequately manage their illness" (PRPC, 2012b, p. 2). More specifically, PSS staff identifies patients needing follow up care based on distress levels greater than five on a scale of 0–10 or when patients request resources or a desire to be contacted. Ideally, staff makes contact with patients in need of follow up care in person at the Cancer Partnership or by telephone within 72 hours. Further assessment is completed at that time and an attempt is made to connect patients with appropriate resources and services, including interventions facilitated by PSS staff.

The inclusion of this a brief assessment tool helps PRCP providers detect and assist in alleviating cancer-related distress and introducing patients to the spectrum of support services

available to them. During PRCP's first year as a free-standing cancer treatment facility, PSS completed more than 4,479 DA questionnaires, with 22.6%, or 1,013 DA forms, indicating distress levels greater than five (PRCP, 2009). The most frequently identified concerns at that time were depression ($n = 7.1\%$), fears and nervousness ($n = 6.4\%$, $n = 5.2\%$), and sleep ($n = 4.3\%$). In 2013, a review of patient contact from three full-time PSS staff members demonstrated that per each 1.0 staff position, 91 points of contact were made each month and an average of 52 new patients were contacted each month (K. Johnson, personal communication, 2013).

Quality assurance. The NCCN (2016b) recommends systemic guidelines to ensure distress management standards are implemented and monitored thereafter. Institutions are encouraged to establish interdisciplinary committees to oversee distress management policies and evaluate quality of psychosocial care. In doing so, the NCCN recommends an audit of patient care records to (a) confirm a patient's emotional wellbeing has been assessed and (b) determine if any action was taken to address identified psychosocial needs. Systemic quality improvement protocols are encouraged to provide feedback to oncology treatment centers about the quality of psychosocial care including patient satisfaction and quality of life.

As a multidisciplinary center, PRCP has several committees that oversee best practices, strategic, business, and program developments, and compliance with ACoS standards for cancer treatment centers (the reader may find a full list of PRCP committees and their role in supporting program goals in Appendix L). Each department has measures that evaluate patient satisfaction, waiting times, and other indicators of quality care (PRCP, 2009). Some measures are compared to other cancer treatment centers throughout the nation, while others are for internal use only. Psychosocial programming and adherence to distress screening policy and procedures are

overseen by the Medical Director of Psychosocial Services and reported annually to the Multidisciplinary Cancer Committee Quality Assurance. In compliance with NCCN (2016b) standards, patients beginning treatment are identified each month and electronic health records are audited to see if distress screening has occurred within 30 days of treatment. Support group attendance is also reported to the Cancer Partnership administration monthly.

In summary, the most current healthcare standards recognize high quality cancer care reaches beyond biomedical treatment to require the inclusion of psychosocial care. Psychosocial services are necessary to treat the complexity of physical, emotional, social, and economic hardships expected to accompany cancer and the rigors of treatment. Psychosocial interventions have demonstrated efficacy in helping patients adopt positive coping skills that can minimize symptoms of distress and improve overall health (IOM, 2008). Patients who receive psychosocial services in tandem with biomedical services tend to have better quality of living and a lower likelihood of developing severe emotional disorders that can interfere with functioning and healthcare treatment. In addition, these patients report greater satisfaction in their cancer care and greater treatment compliance with provider recommendations (NCCN, 2016b).

In adherence with national initiatives, Providence Regional Cancer Partnership was established as a multidisciplinary outpatient cancer treatment center to meet the biomedical and psychosocial needs of its patients. The following chapters examine how PRCP has addressed the psychosocial needs of its patient population. A program evaluation was conducted to understand how program services delivered by Patient Support Services were (a) utilized and represented across patient demographics and (b) valued or regarded within the larger cancer treatment center. Program strengths provide insight into services that are well utilized and provide support for the efficacy of psychosocial services as part of a larger cancer treatment center. Program

recommendations are offered with input from stakeholders to improve areas of concern identified by patients and staff.

Chapter II: Methodology

While PRCP routinely employs internal quality assurance procedures dictated by the American College of Surgeons (2014) and National Comprehensive Cancer Network (2016b), the organization had not taken an in-depth look at its behavioral health department, Patient Support Services, since its inception in 2007. In particular, to-date, no information had been gathered that analyzes how program services are utilized and by whom; additionally, program satisfaction data had not been collected since 2009. This evaluation sought to understand and evaluate the merit of PRCP's psychosocial services department and to provide program feedback. A stakeholder meeting was held to generate areas of interest from the perspective of PRCP's leadership team as well as clinical and support staff. The nature of this evaluation included gathering qualitative and quantitative data from patients and staff to understand how program services were currently utilized and regarded from the perspective of program recipients, clinical staff, and administrators. Evaluation findings provided informed and contextualized recommendations to further benefit PRCP's staff and patient population.

Program Evaluation

This study utilized program evaluation as a methodology to evaluate psychosocial services provided at PRCP. As a method, program evaluation evaluates questions concerning a program's utilization, implementation, or efficacy of services (W. K. Kellogg Foundation, 2004a). At its core, program evaluation seeks to determine the merit of the subject being studied; a judgment is rendered about the worth or value of the subject being studied. Herein lies the primary difference in purpose between research and evaluation methods: Research contributes information to a field by providing conclusions; whereas, evaluation aims to help stakeholders make informed decisions based on judgments (Fitzpatrick, Sanders, & Worthen, 2004). Unlike

research, which culminates in a discussion of how results are generalizable, program evaluation concludes with a report of evaluation findings and program recommendation specific to the organization.

Formative program evaluation. More specifically, a formative program evaluation framework was used in this study based on the primary purpose and intended audience of the evaluation. Formative evaluations intend to provide feedback for the purpose of program improvement, providing information on the merit or worth of part of a program rather than the entirety of a program (Fitzpatrick et al., 2004). Such evaluations focus on examining program activities, outputs, and short-term outcomes to monitor progress and recommend midcourse corrections as needed (W. K. Kellogg Foundation, 2004b). Questions typically asked throughout a formative evaluation may include: What aspects of the program are working? What elements need to be improved and how?

The intended audiences who will benefit from this evaluation are the people delivering program services, namely Patient Support Services staff and program administration; program recipients will benefit secondarily from recommendations aimed to improve program services.

Stakeholder Meeting

Engaging stakeholders in the evaluation process, particularly during the question development phase, was prudent in ensuring a useful and credible project. Because stakeholders are invested in the organization's success and affected by the evaluation findings, their input was necessary and invaluable in determining the scope and direction of this evaluation. As noted by Preskill and Jones (2009), evaluation findings are more likely to be relevant, accepted, and implemented by the organization when research questions reflect the interests and needs of vested members.

Members of the PRCP Psychosocial Steering Committee were invited to participate as stakeholders. The Psychosocial Steering Committee is a multidisciplinary team responsible for “planning and implementing program and service development to meet the psychosocial needs of cancer patients” (PRCP, 2012a, p. 2). Because the committee oversees psychosocial program development, the quarterly meeting was chosen as the forum to invite members to participate as stakeholders in shaping the proposal of this project and brainstorming possible areas of evaluation. In total, 10 members participated in the first stakeholder meeting including members of the management team as well as supporting specialists and clinical staff. Although program recipients may also be considered stakeholders as the beneficiaries of program services, patients were not invited to stakeholder meetings because the primary audience of this evaluation was persons delivering program services rather than its consumers.

Members present at the stakeholder meeting expressed support and enthusiasm for the evaluation. Several areas of interest were generated and later categorized by the evaluator based themes and areas of focus defined by Fitzpatrick et al. (2004): needs assessment or context, process and monitoring, or outcomes. What follows are areas of evaluation proposed during the stakeholder meeting (the reader may refer to Appendix M to review notes from the first stakeholder meeting).

Needs assessment or context. This area of evaluation explores program aspects perceived of being in need and attempts to mitigate problems through program recommendations:

- What is the purpose and value of Patient Support Services?
- How does PRCP compare to other cancer treatment centers or Providence campuses throughout the region?

Process and monitoring. These questions seek to understand how program services are delivered:

- Is the current model of training and delivery of psychosocial program services sustainable over time?
- Is the mission of Patient Support Services still appropriate? Is the program doing what we said it would and is it doing it well?
- How are program services utilized by patients? Are there groups of patients not being served by PSS?

Outcomes. Outcome questions explore how program recipients are changed through their participation in a program:

- What is the patient and/or staff experience of PSS?
- What is the cost and savings benefit of the larger Cancer Partnership because of the inclusion of psychosocial services in cancer treatment?
- What is the impact of having PSS within the larger cancer treatment program and how does it affect the role of other staff members?

Stakeholders continued to be involved throughout the development of this evaluation. A second stakeholder meeting took place prior to data collection to discuss design considerations, sources of available data, and data collection methods. The Medical Director of Psychosocial Services was closely involved in all phases of this evaluation, ensuring program support and interest throughout the entirety of the evaluation. Stakeholders were again included at the conclusion of data analysis to participate in generating proposed program recommendations based on evaluation findings.

Outcomes Approach Logic Model

Following the initial stakeholder meeting, a logic model was developed to provide clarity in understanding the presumed relationship between program services, program goals defined by the department's mission, and the desired outcome of program services. Logic models visually depict the relationship between a program's theory and assumptions about how the program works (W. K. Kellogg Foundation, 2004b). More specifically, logic models are helpful in illustrating the sequence of activities necessary to facilitate desired changes and bring about anticipated results. In this way, logic models can serve as a roadmap to guide stakeholders and the evaluator in understanding the relationship between the program's goals and the results the program expects to achieve.

For this evaluation, an outcomes approach logic model was chosen to illustrate the assumed causal relationships between PSS program services and the program's anticipated outcome, to mitigate the psychosocial distress of cancer patients and their family members. Appendices N and O illustrate the outcomes approach logic model used in this evaluation to better understand the relationship between program services and desired outcomes.

Evaluation Questions

Evaluation questions were formulated with input from PRCP stakeholders and refined using program evaluation theory and methodology. Formative program evaluation methods provided the scope for this project, while an outcomes approach logic model provided clarity in understanding the relationship between program activities or services (i.e., input) and desired outcomes or expected results participating in services (i.e., output). Finally, project feasibility was also considered when identifying evaluation questions. Congruent with formative evaluation

practices, this evaluation aimed to provide feedback about particular aspects of PSS, rather than the program as a whole.

The predominant purpose of this formative evaluation was to provide PRCP feedback about the merit or worth of Patient Support Services. To this effect, the evaluator examined both utilization and satisfaction of Patient Support Services to better understand how program services were (a) utilized and represented across patient demographics and (b) valued or regarded within PRCP, as defined by patient and staff satisfaction. A mixed method approach was used to collect and analyze data. Archival data was gathered from electronic health records to determine how program services were utilized and by whom. Two surveys were designed and distributed to understand the experiences and opinions of program services.

Participants

Demographic information was collected from electronic health records to identify a representative sample of patients who utilize program services. Additionally, program feedback was collected from patients and staff members including program administrators, clinical providers, and support staff persons.

Patient chart reviews. Four hundred chart audits were decidedly selected from an overall sampling of patients who received cancer treatment at PRCP. Electronic health records were chosen for review based on patient participation or interaction with PSS staff within twelve months of this evaluation being conducted. Participants were selected from charting records based on documentation of daily patient interactions provided by three PSS staff members. Patient information was then located using PRCP's data information system which manages electronic health records. Participants were excluded if patient names were unable to be located in the electronic health record. These names likely accounted for patients with misspelled names,

family members calling on behalf of patients, or persons receiving treatment elsewhere but calling PSS for information or resources. Additionally, participants were excluded if a cancer diagnosis was unsubstantiated based on documentation (i.e., benign masses or tumors). On occasion, hematology patients were included if they received treatment from an oncologist/hematologist and participated in program services.

Patient surveys. Patients were also selected to receive surveys. This selection process occurred a number of ways to account for patients who were currently receiving treatment as well as patients who had completed treatment in recent months. Patients were offered satisfaction surveys if they were receiving treatment onsite during a four month period while this evaluation was being conducted. Patients attending a support group during this evaluation were also invited to participate in surveys. Lastly, patients were selected to receive a survey by mail if they had attended an initial oncology office visit in the year prior to this evaluation being conducted. Known deceased patients were excluded from the mailing list.

Staff surveys. PRCP staff was invited to participate in an online survey to gather feedback about Patient Support Services. Staff who had direct or indirect interaction with patients and/or PSS staff were eligible to participate in the survey. Staff members included program administrators, clinical providers, and support staff persons. Members of Patient Support Services were excluded.

Materials and Measures

Chart reviews. Demographic information was collected from electronic health records to better understand how program services were currently represented and utilized by patients. Patient demographics were defined and described as follows:

Age. Age was determined at the time of data collection according to date of birth. Age was then collapsed into groupings by age range as follows: 18–25, 26–34, 35–44, 45–54, 55–64, 65–75, 75 and older.

Gender. A binary gender classification was used to categorize patients as either male or female based on documentation gathered from electronic health records.

Insurance. Primary health insurance information was collected and then collapsed into three categories: private or commercial, Medicare, and Medicaid or state-sponsored insurance. Insurance information was used to generate inferences about socioeconomic status and access to resources.

Cancer type. Type of cancer, or primary cancer site, was determined by the oncology team. Diagnoses were identified according to an initial oncology appointment and confirmed based on the most recent office visit to account for any diagnostic changes that may have occurred based on later imaging and pathology findings. In 2015, PRCP treated the following primary cancers:

- Bladder cancer
- Brain tumors
- Breast cancer
- Cervical cancer
- Colorectal cancer
- Endometrial cancer
- Esophageal cancer
- Gallbladder cancer
- Gastrointestinal tumors

- Head and neck cancer
- Kidney cancer
- Leukemia
- Liver cancer
- Lung cancer
- Lymphomas
- Ovarian cancer
- Pancreatic cancer
- Skin cancer
- Soft tissue sarcoma
- Uterine cancer

Several oncologists at PRCP also treat a variety of hematologic malignancies or blood diseases, including problems affecting blood cells, platelets, blood vessels, bone marrow, lymph nodes, and proteins that affect bleeding and clotting (American Society of Hematology, 2015).

Hematology patients also had access to Patient Support Services and, therefore, were included in this evaluation on the rare occasion that they participated in program services.

In general, International Classification of Diseases (ICD-9CM) (WHO, 2015) coding system was used to classify cancers based on primary site. For analysis, less commonly occurring cancers and malignant disorders were grouped together by their relationship as follows:

- hematologic diseases: anemia, coagulation disorder, thrombocytosis and thrombocytopenia, and myelodysplastic syndrome;
- blood cancers: lymphomas, leukemias, multiple myeloma;

- female reproductive cancers: vaginal and vulvar, cervical, uterine and endometrial, ovarian, and urethral cancer;
- male reproductive cancers: penile, prostate, and testicular cancer;
- head and neck cancers: oral cavity, pharynx, larynx, paranasal sinuses and nasal cavity, salivary glands, and thyroid cancer;
- skin cancers: basal and squamous cell, melanoma, merkel, and Kaposi;
- colon, rectal, and intestinal cancer;
- liver and hepatocellular cancer and bile duct cancer; and
- squamous cell carcinoma of unknown primary site

Cancer staging. Clinical stage was determined at diagnosis by the oncology team, prior to starting treatment. Staging describes the progression and severity of cancer based on the size of the tumor and the extent cancer has spread beyond the original tumor into nearby tissues and organs or into the bloodstream or lymphatic systems (ACS, 2015b). Staging provides inferences about treatment options as well as prognosis, including chance of survival and the likelihood of cancer recurring. Most cancers are classified as one of five stages, with higher stages indicating more extensive disease progression (National Cancer Institute at the National Institutes of Health [NCI], 2015):

- Stage 0: Abnormal cells are present, but have not spread to nearby tissue. At this stage, abnormal cells are not cancerous, but may later become cancer.
- Stage I: Cancer growth is limited to the primary organ site without evidence of metastases, or growth beyond the original tumor.
- Stages II & III: Cancer has spread beyond the primary organ to nearby lymph nodes, tissues, and/or organs.

- Stage IV: Cancer has spread to distant lymph nodes, tissues, and/or organs.

There are several exceptions to the staging classification system described above. For example, cancers of the blood or bone marrow rely on a different staging system that considers blood cell counts and may use a three-stage classification system (0–III) rather than five (ACS, 2015a; ASCO, 2015; Leukemia and Lymphoma Society, 2015). Because a variety of factors determine cancer staging, including the number of staging classifications (typically three verses five), true comparisons between cancer stages across cancer types could not be made. However, during data analysis, it was assumed that higher stage numbers were indicative of more extensive disease progression, irrespective of cancer type or classification system.

Medical treatment. PRCP (2014) provides a wide variety of medical treatments including prevention screening, diagnostic services, clinical research, medical oncology, radiation oncology, and psychosocial services. This evaluation identified whether patients received surgical oncology, chemotherapy, radiation, or a combination of medical services. Data analysis looked at trends in the utilization of program services according to medical oncology treatment.

Program services. Participation in program services was recorded based on documentation from PSS staff. While PRCP offers a variety of support services and integrative medicine including acupuncture, yoga, hypnosis, meditation, and naturopathic medicine, this evaluation focused on services provided by PSS staff. Namely, this evaluation was interested in tracking patient interaction related to telephone contact, Distress Assessment questionnaires, supplemental financial services, counseling during infusion, office visits, support groups, and family involvement in services. Information was also collected about patient participation in the Cancer Resource Center and nutrition services because of the close involvement the patient navigator and dietician had with PSS. Support groups facilitated by PSS staff were included;

however, data was not collected from the Look Good, Feel Better class facilitated by the American Cancer Society, the prostate cancer support group facilitated by a cancer survivor, or gentle yoga led by yoga instructors unaffiliated with PSS.

The number of interactions with PSS was determined based on staff documentation; any interaction with PSS staff, the patient navigator, or dietician was included for data analysis and not limited to a specific timeframe. While patient participation in support groups was included, the number of times a patient attended a support group was not calculated

Surveys. Two surveys were designed to gather information from the perspective of patients, or program recipients, and staff members. Surveys were developed with input from PSS staff and designed to elicit respondents' experiences and opinions about program services and staffing, drawing out program strengths and weaknesses. Respondents' attitudes were measured using fixed-choice Likert scales intended to increase the likelihood and ease of participating in surveys.

Patients were asked about their familiarity with the department and program services, utilization of services, satisfaction regarding the quality and variety of program services as well as staffing, opinions about the impact program services had as part of their cancer care treatment, and perceived strengths and areas for improvement. Similarly, PRCP staff were surveyed about their familiarity with the department and program services, the referral process (how often, which services, and under what circumstances program services were recommended by staff), perceived strengths and areas for improvement, and opinions about the importance or value of including behavioral health services in a cancer treatment program. Copies patient and staff satisfaction surveys are included as Appendices P and Q.

Procedures

Patient chart reviews. Four hundred electronic health records were reviewed to gather information on patient demographics, general treatment information including cancer origin and stage, treatment modalities, and participation in Patient Support Services. Information was gathered from electronic health records, particularly physician treatment notes, PSS staff documentation, and patient demographic information.

Patient surveys. Patient surveys were distributed both in person and by mail to capture a large pool of participants and to mitigate low return rates typical of surveys. Surveys were initially offered to patients by reception staff upon checking in for chemotherapy or radiation treatment. A secure box was provided to anonymously return completed surveys in common waiting areas. However, due to a low volume of surveys returned in person, surveys were mailed to patients' homes. Preaddressed envelopes with prepaid postage were included for easily return completed surveys to PRCP. Four hundred and forty surveys were mailed to patients who began treatment between July 1 and October 1, 2014. This treatment timeframe was selected to avoid sending surveys to patients who were currently receiving treatment onsite, minimizing the possibility of surveying people on more than one occasion.

In addition, American Cancer Society volunteers offered surveys to patients during chemotherapy infusion. It was conceived that patients would be more likely to complete surveys during treatment, which often lasts several hours, rather than during an office visit with their oncologist. Presumably, patients would be more receptive to complete surveys hand-delivered by volunteers during treatment than by reception who routinely distribute patient paperwork upon checking in. Lastly, PSS staff distributed surveys during support group meetings between August–September 2015. In total, 590 surveys were made available for distribution in person and

by mail. Patient surveys were printed on colored paper to monitor how surveys were returned and by whom.

Staff surveys. One hundred and ten eligible staff were invited to anonymously participate in a survey via Survey Monkey. An initial email invitation read, “Please consider participating in the following survey to provide feedback about Patient Support Services. Your input is extremely valuable in shaping ongoing and future services. Your participation is voluntary and anonymous. It should take no longer than ten minutes to complete. Thank you for your feedback.” A second email invitation was sent by the evaluator 2–4 weeks later with the following request, “Patient Support Services needs your feedback. If you have not already responded, please complete the survey using the link below. We are very interested in hearing from you so we can strengthen and improve services we provide to our patients each year. It is a quick anonymous survey, but your feedback is invaluable. Thank you.”

Data Analysis

Data from electronic health records and surveys were analyzed to (a) identify trends in the utilization of program services and the patients who use them, and (b) draw out themes regarding the quality, variety, and efficacy of program services and staffing. Data analysis decisions were informed by the goals of this evaluation with the intention of providing feedback to staff delivering program services and administrators. Additionally, data analysis was informed by the characteristics and statistical assumptions of the data set (Salkind, 2007).

Chart reviews. Data collected from electronic health records was recorded into Excel for tracking, coding, and analysis. Utilization of services data relied heavily on the use of descriptive statistics to describe the characteristics of program participants and services used. A majority of the data collected was categorized as a nominal level of measurement including gender,

insurance information, cancer diagnosis, and program services. Ordinal (cancer stage) and ratio levels of measurement (age, number of PSS visits) were less likely to characterize the data set. Participants were categorized into three groups based on their level of participation in program services, as described in the following chapter on evaluation results. Descriptive statistics were used to describe the characteristics of each participant group and make comparisons between groups to understand how services were used. Frequency charts were used to visually depict the occurrence of demographics and to illustrate the majority and minority characteristics of program users. Percentage rates and frequencies were often reported together to describe the characteristics of data; percentage rates demonstrated frequencies in relation to the sample population. Measures of central tendency described the average age range, the mean cancer stage, and average number of program services used.

Inferential statistics were used to compare data to other points of reference. Nonparametric statistics allowed the data to be examined based on rules of distribution and the relationship between variables (Salkind, 2007). This data set relied on one-sample chi-square analyses to make inferences about demographic information compared to PRCP's patient population at-large. When appropriate, chi-square analyses were also conducted to compare the distribution of demographics between program participants and corresponding national data.

Surveys. All survey data was entered in SurveyMonkey for analysis. Similar to chart reviews, survey data heavily relied on descriptive statistics to explain findings. Demographic information was collected to describe the representative patient and staff sample. Frequency charts and pie charts were used to visually represent results; while frequency charts illustrated the overall tally of a variable, pie charts demonstrated values in proportion to the sum of the data.

The majority of survey questions measured respondents' attitudes towards a statement using fixed-choice Likert-scales. Data from Likert-scales was represented using percentage rates and frequencies to quantify responses. Other questions contained multiple choices and respondents were free to select as many that applied. Again, percentage rates and frequencies depicted how often a response was endorsed and how it compared to the overall sample. Lastly, one open-ended question solicited feedback about suggested program areas for improvement. Responses were synthesized into shared categories based on observed themes and reported using respondents' language.

Risks and Ethical Considerations

Patients. The presumed risks of participating in surveys was deemed minimal, though worthy of consideration. First, cancer patients may be perceived as a vulnerable population given the acuity and/or chronicity of their disease and their dependence on medical providers for appropriate treatment (Managed Care and Healthcare Communications, 2006). The vulnerability of participants is further realized as additional factors are taken into account such as race, gender, socioeconomic status, education, and level of psychosocial distress or mental illness. As a vulnerable population, patients may have felt uncomfortable participating or unable to decline participating. Patients may have felt pressure to participate in this evaluation given the difference in power and status between patients and their providers. Although participation was voluntary and feedback was anonymous, patients may have felt uncomfortable or guilty providing critical feedback because of their reliance on the institution for life-prolonging treatments. Critical feedback may have been inhibited for fear of repercussions if patients expressed criticism of an organization they depend on for care.

Staff. PRCP staff faced similar risks participating in this evaluation. Most notably, PRCP staff may have been reticent to participate for fear of being identified and experiencing retaliation. While the staff survey was designed to be anonymous, staff were asked to identify their position and number of years employed, which threatened their anonymity. For example, some staff positions, such as advanced care practitioners, represented a very small portion of overall staff and, thus, such identifiers significantly reduced the anonymity of staff. A second consideration was the dual relationships this evaluator had with several staff members which is discussed further in the next section. Dual relationships may have compromised respondents' objectivity or ability to provide critical feedback.

Disclosure of roles and relationships. From 2013–2014, I was a full-time predoctoral psychology intern in Patient Support Services at PRCP. Following the completion of my internship, I obtained employment with The Everett Clinic, one of the organizations that comprise the partnership of PRCP. I have maintained personal and professional relationships with many of the people I worked with at PRCP, including current PSS staff and the Medical Director of Psychosocial Services, Dr. Kathryn Johnson who helped facilitate this evaluation and served as a committee member for my dissertation defense.

My involvement in PSS created advantages and disadvantages as an internal evaluator. Foremost, the decision to evaluate the efficacy of PSS grew out of my personal involvement with the organization and my affection for the program's mission to mitigate the psychosocial distress of persons affected by cancer. As a former intern, my relationships with the staff at-large facilitated a trusting and collaborative atmosphere; relationships that were cultivated years prior helped foster the necessary involvement of staff as vested stakeholders who shaped the development, execution, and utility of this evaluation. My intentions to evaluate the program

were also assumed to be benevolent and beneficial. I was regarded as an expert of psychosocial services based on my intimate knowledge and experience of the department's workings including program development and services, the history, mission, and goals of the program, the patient population, and PSS's position within PRCP. Further, my understanding of the organization's systemic and political values helped design an evaluation that was of interest to PRCP and in alignment with their goals and mission.

Conversely, my role as an internal evaluator could also be viewed unfavorably. While my history with the program helped facilitate the execution of this evaluation, it also contained a biased perspective. Whereas an external evaluator may have brought a more objective and arguably more credible perspective to the evaluation process, my relationship with the organization likely influenced the interpretation of the results. Indeed, my affinity for the program and its success likely influenced how feedback was interpreted and later integrated into recommendations. It is likely I analyzed program feedback with an "opportunistic bias," unconsciously searching for feedback that confirmed own ideas about the program's strengths and weaknesses (De Coster, Sparks, Sparks, Sparks, & Sparks, 2015). To account for evaluator bias, participants were invited to offer explicit feedback about their perception of program strengths and weaknesses, openly encouraging critical feedback. Additionally, stakeholders participated in interpreting findings and formulating recommendations, which helped provide a more pluralistic understanding of feedback and challenge the evaluator's preconceived notions about expected findings.

As an internal evaluator, I had little insulation when it came to scrutinizing data and presenting results to the organization. Critical feedback needed to be presented accurately and thoughtfully without fear of jeopardizing my relationships within the organization. Additionally,

dual relationships with staff as both participants and colleagues or friends blurred the boundaries of the evaluation at times, especially as the design and scope of this evaluation were considered. Limitations of this evaluation had to be identified and clearly negotiated early on to establish the parameters of this project and shield the evaluator from potential repercussions. Again, the close involvement of stakeholders proved essential in conducting an evaluation that was fair and mutually agreed upon. Further, the involvement of stakeholders throughout the entirety of this evaluation reduced elements of surprise or confusion and prepared stakeholders for constructive findings at the conclusion of the evaluation.

Chapter III: Results

Results of this evaluation provided Providence Regional Cancer Partnership feedback about the merit or worth of Patient Support Services. To this effect, the evaluator examined both utilization and satisfaction of PSS to better understand how program services were (a) utilized and represented across patient demographics and (b) valued or regarded within the cancer treatment center. Results provided a snapshot of program services as they were currently utilized and valued from which informed recommendations were generated based on perceived program strengths and areas for improvement.

Utilization of Services

Demographic information was collected from PRCP patients to better understand how program services were currently represented and utilized. Information was gathered from the electronic health record of 400 patients who participated in a least one program service during the 12 months prior to this evaluation. Information was collected on patient demographics (age, gender, insurance information), general diagnostic information (cancer origin and stage), treatment modalities (surgery, chemotherapy, radiation), and participation in program services (telephone contact, distress assessment, Cancer Resource Center, nutrition services, financial services, support during infusion, office visit, support groups, family services).

Demographics of patients who participated in program services were compared to demographics of all new patients at PRPC during the same timeframe. Program recipients were categorized into three groups for analysis based on their level of participation in program services, defined as follows: (a) single-use participants: patients who participated in program services once ($n = 89$), (b) multiuse participants: patients who participated in program services on more than one occasion ($n = 212$), and (c) group participants: patients who participated in one

or more support groups ($n = 99$). Demographic information was analyzed to understand how utilization of program services compared and contrasted among the three groups. Data was then aggregated again to further compare program services between groups.

All new cancer cases. According to the American Cancer Society (ACS, 2014a), there were 38,230 new cancer cases in Washington State in 2014. During the time of this evaluation, PRCP saw 1,904 new cancer cases. Of those, 44% were male and 56% were female. Patients were most likely to be between the ages 60–69 ($n = 30\%$). Patients between the ages 70–79 were also highly represented, constituting 25% of all new patients. Patients under the age of 49 represented 13% of all new cases.

Table 2

Percentage Rates and Frequency of Demographics: New Cancer Cases

	Percentage	Frequency
Gender		
Male	44.0%	837
Female	56.0%	1,067
Participants Age		
0 to 29	2.1%	40
30 to 39	3.0%	58
40 to 49	8.0%	153
50 to 59	19.0%	360
60 to 69	30.2%	575
70 to 79	24.6%	469
80 to 89	11.1%	211
90 or older	2.0%	38

According to national statistics on gender and cancer incidences reported by ACS (2014b), the number of all new cancer cases per men was 855, 220 ($n = 51.3\%$), while new cancer cases per women was 810, 320 ($n = 48.7\%$). A chi-square analysis was conducted to determine if the distribution of men and women constituting new cancer cases at PRPC was meaningful or likely due to chance based on ACS (2014b) national gender and incidence rates.

Results from the chi-square analysis suggested the distribution of men and women was meaningful ($X^2_{(1)} = 41.06$, $p < 0.05$). Indeed, PRCP observed lower frequencies of men ($n = 44\%$) and higher frequencies of women ($n = 56\%$) than expected according to national averages.

The age range of new patients seen at PRCP was roughly compared to national estimates of all cancer cases based on ACS (2014b) data. An exact comparison was not possible due to the different intervals used to calculate age ranges. Even so, differences between PRCP cancer cases and national data could be inferred. While national data estimated persons older than 65 represent the majority of new cancer cases ($n = 54.3\%$), PRCP's greatest range of new cancer cases was represented by patients age 50–69 ($n = 49.1\%$). Presumably, PRCP saw a higher incidence of new cancer cases among persons age 50–69 than estimated according to ACS statistics ($n = 37.2\%$) and fewer incidences of new cancer cases among persons older than 70.

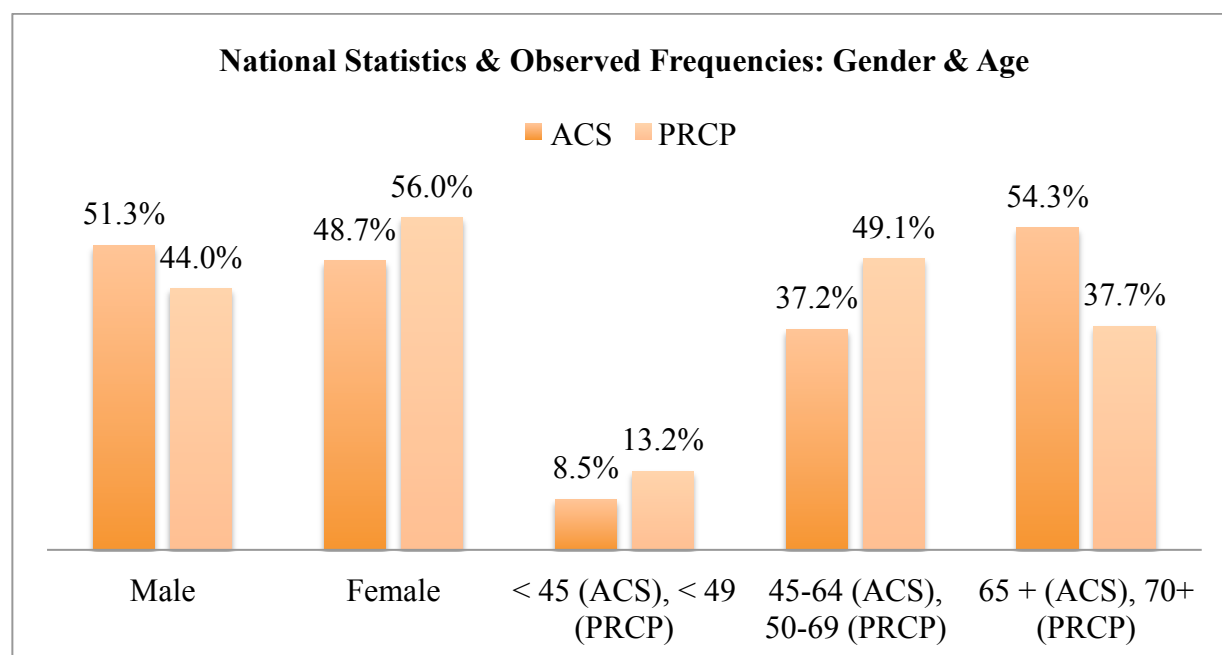


Figure 2. National statistics and observed frequencies: gender and age. Estimated new cancer cases by gender and age, American Cancer Society (2014b).

Table 3

Chi-square Analysis: New Cancer Cases by Gender

	(O) Observed Frequency	(E) Expected Frequency*	(D) Difference	(O-E)²	(O-E)²/E
Men	837	977	140	19,531	20.00
Women	1,067	927	-140	19,531	21.06

Note. Expected frequencies were based on American Cancer Society (2014b) statistics of new cancer cases by gender.

Among all new cases of cancer seen at PRCP, more than fifty percent of patients had Medicare insurance as their primary payer ($n = 1002$). High incidences of Medicare coverage coincided with the average age range of patients seen at PRCP, the majority being older than 60 ($n = 1293$). Because most people age 65 and older qualify for Medicare coverage (Centers for Medicare & Medicaid Services, 2014), and 68% of all new cancer patients at PRCP were over the age of 60, it was not surprising that 54% of all new cancer patients possessed Medicare insurance. Of all new cancer cases, 38% of PRCP patients possessed commercial coverage while 7.5% had Medicaid (see Appendix F for a full report, PRCP Incidence of Cancer by Site and Primary Payer Report).

In general, patients' health insurance coverage differed from the distribution of health insurance across the general population. According to the U. S. Census Bureau, 55.4% of the general population possesses private health insurance, 16% receive Medicare, and 19.5% receive Medicaid (Smith & Medalia, 2015). Comparatively, PRCP's sample was represented by 38.1% commercial insurance users, 53.6% Medicare, and 7.5% Medicaid recipients. While the large variance of Medicare users could be attributed to the high volume of persons diagnosed with cancer later in life, commercial and Medicaid users still appeared to be underrepresented, even when patients over the age of 60 were excluded from the sample ($n = 611$). In particular, based on U. S. Census Bureau estimates, Medicaid users appeared to be especially underrepresented

among new cancer cases at PRCP. This discrepancy may reflect the organization's decision to restrict the number of persons accepted for treatment with Medicaid coverage.

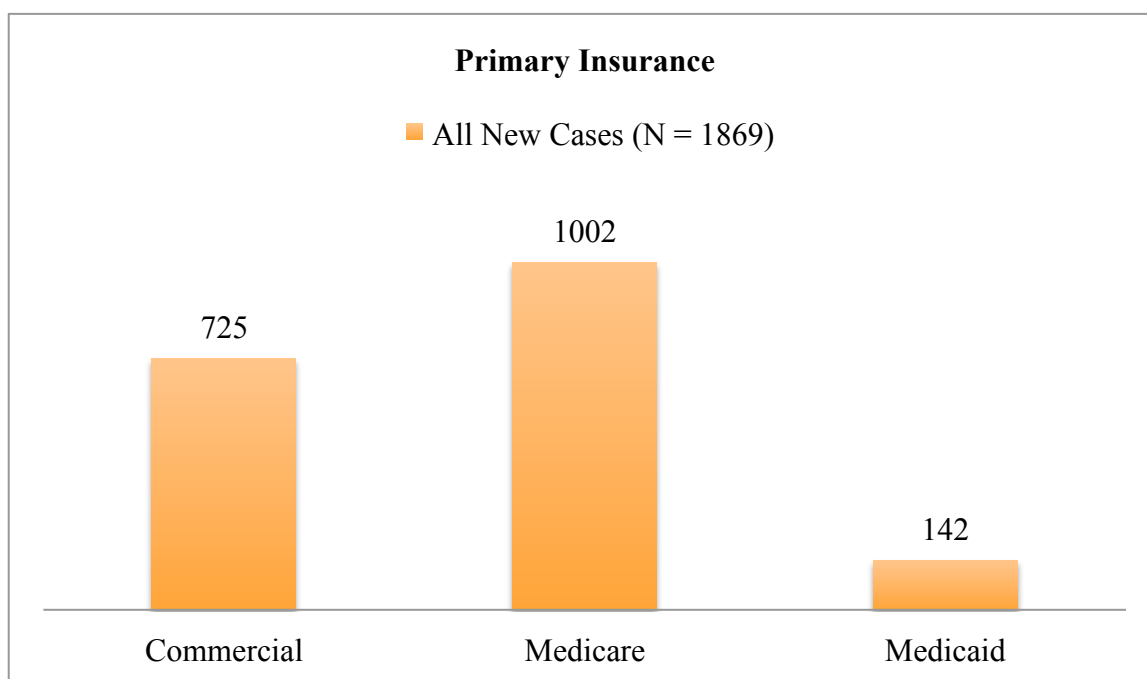


Figure 3. Distribution of primary insurance: all new cancer cases.

In 2014, the most commonly occurring cancers at PRCP were breast ($n = 370$) and lung ($n = 275$). Female reproductive ($n = 178$), blood cancers ($n = 163$), and colorectal cancer ($n = 151$) were also well represented among new cancer cases. Pancreatic ($n = 36$), brain ($n = 33$), and liver cancers ($n = 25$) were less common among new cancer cases.

The National Cancer Institute (NCI, 2016) projects breast, lung, prostate, colorectal, bladder, melanoma, renal, leukemia and lymphoma, endometrial, and pancreatic cancers to be the most common cancers among new cancer cases diagnosed in 2016. A chi-square analysis was conducted to compare all new cancer cases at PRCP to expected prevalence rates across the United States. Specifically, a chi-square analysis was used to determine if the distribution of observed cancer cases at PRCP was representative of national cancer prevalence rates predicted by NCI. Results from the chi-square analysis suggested the distribution of cancer among all new

cases was not due to chance alone, indicating discrepancies between expected and observed prevalence rates ($X^2_{(11)} = 245.87, p < 0.05$). Indeed, compared to national estimates, PRCP saw a greater number of breast, lung, and female reproductive cancers than was expected. Conversely, PRCP saw fewer male reproductive cancer patients than expected. The remaining cancer types—brain, head and neck, liver, pancreatic, bladder, colorectal, blood, and skin cancers—appeared to be representative of expected prevalence rates.

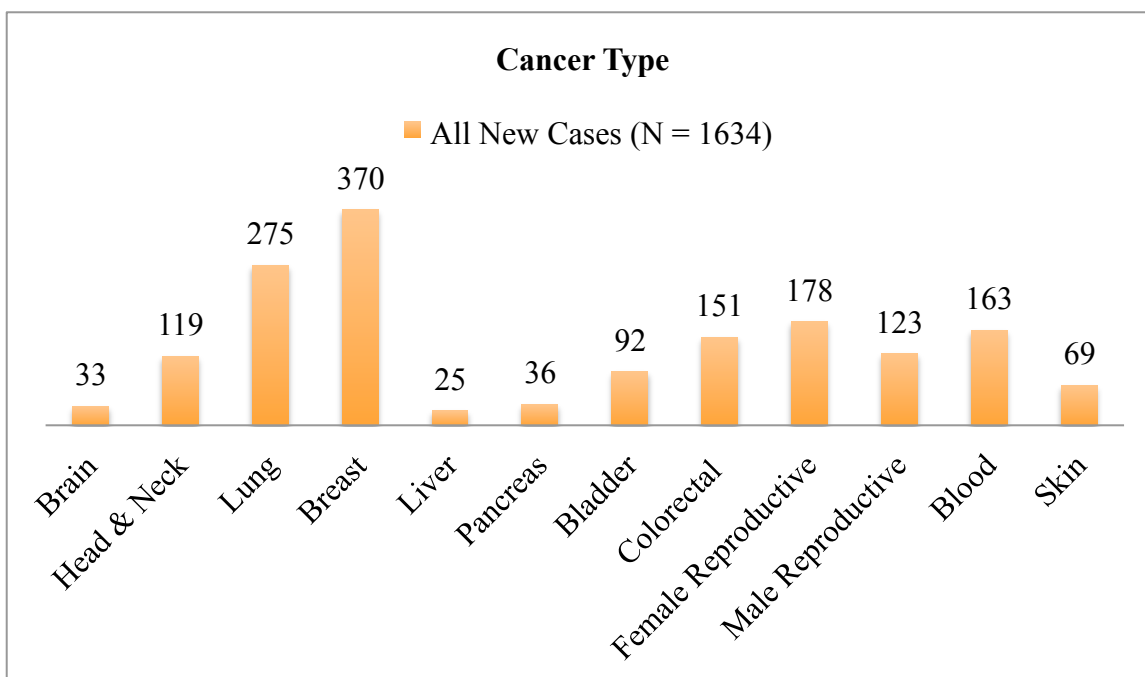


Figure 4. Distribution of cancer type: all new cancer cases.

Table 4

Chi-Square Analysis: Cancer Type Among All New Cancer Cases

	(O) Observed Frequency	(E) Expected Frequency*	(D) Difference	(O-E) ²	(O-E) ² /E
Brain	33	23	-10	102	4.48
Head & Neck	119	137	18	333	2.43
Lung	275	217	-58	3,327	15.30
Breast	370	229	-141	19,949	87.20
Liver	25	36	11	120	3.33
Pancreas	36	49	13	170	3.46
Bladder	92	74	-18	341	4.64
Colorectal	151	141	-10	110	0.78
Female	178	93	-85	7,202	77.32
Reproductive					
Male	123	225	102	10,505	46.59
Reproductive					
Blood	163	160	-3	8	0.05
Skin	69	74	5	21	0.28

Note. Expected frequencies were based on the occurrence of cancer subtype as compared to all new cancer cases estimated in 2015, as indicated by the National Cancer Institute (2016).

The distribution of cancer stage was difficult to predict as cancer staging varies based on cancer type (i.e., breast versus lung cancer) and available cancer screening or detection methods (Canadian Partnership Against Cancer, 2016); therefore no comparison data were available to determine differences in the distribution of cancer staging between all new cancer cases at PRCP and expected values.

The majority of all new cancer cases were represented by stage I cancer ($n = 29.5\%$). Stage II and stage IV cancer were similarly represented among new cancer cases as 17.1% and 19.7%, respectively. Stage III cancer was less likely to be represented among new cancer cases, second to stage 0 cancer.

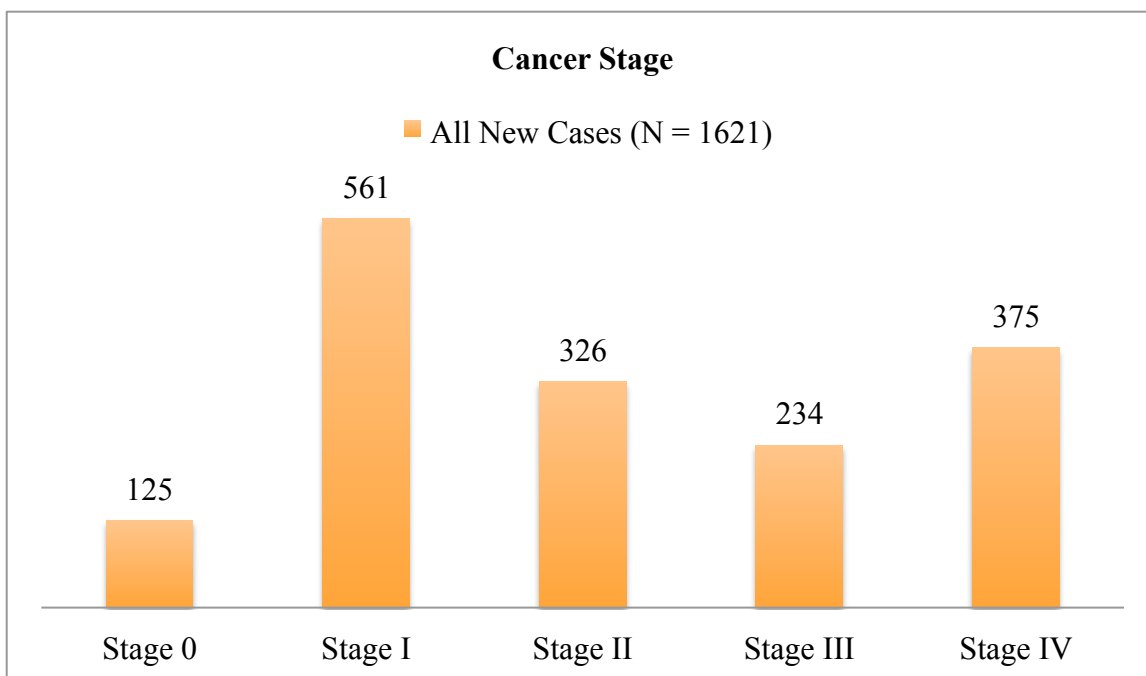


Figure 5. Distribution of cancer stage: all new cancer cases.

Single-use program participants. Eighty-nine participants used services on one occasion with no additional follow up. Forty-two percent of single-use participants were male, while 58% were female. The majority of single-use participants were between the ages 65–74 ($n = 36\%$) and the mean age was 66.9 (median = 68, mode = 68). An additional 26% of single-use participants were 75 or older while 24% were between the ages 55–64. Single-use participants were less likely to be under the age of 54 ($n = 15\%$).

Table 5

Percentage Rates and Frequency of Demographics: Single-Use Participants

	Percentage	Frequency
Gender		
Male	41.6%	37
Female	58.4%	52
Participants Age		
26 to 34	1.1%	1
35 to 44	3.4%	3
45 to 54	10.1%	9
55 to 64	23.6%	21
65 to 74	36.0%	32
75 or older	25.8%	23

Not surprisingly, because of its prevalence among all new cancer cases at PRCP, breast cancer was well represented among single-use participants. The majority of single-use participants were diagnosed with breast cancer ($n = 25$), while lung ($n = 12$) and colorectal cancer ($n = 11$) represented the second and third most prevalent cancer types among single-use participants. The remaining 64 participants represented a variety of cancer diagnoses.

Because all patients receive screening for psychosocial distress based on NCCN (2016b) standards, single-use participants were expected to broadly represent cancer types relative to the demographics of all cancer cases treated at PRCP. A chi-square analysis was conducted to determine if the distribution of cancer diagnoses among single-use participants was representative of new cancer cases at PRCP. Results from the chi-square analysis, did in fact, suggest the distribution of cancer among single-use participants was equal to what was expected compared to PRCP data on all cancer cases ($X^2_{(10)} = 15.20$), although breast cancer was significantly represented more frequently than expected.

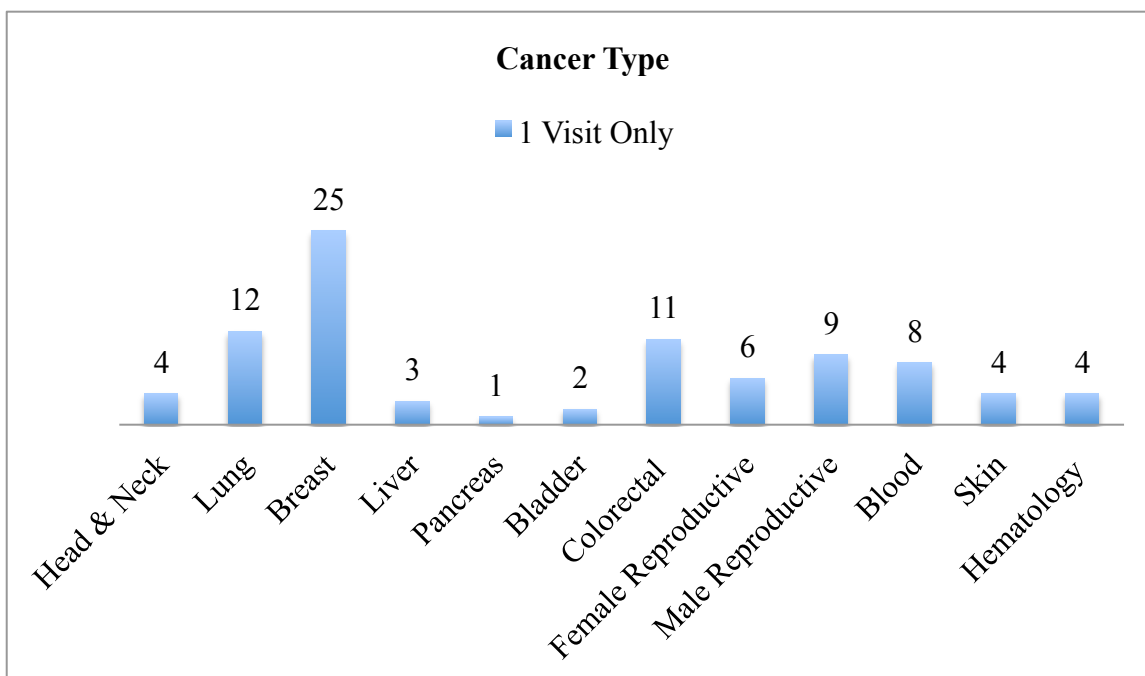


Figure 6. Distribution of cancer type: single-use participants.

Table 6

Chi-Square Analysis: Cancer Type Among Single-Use Participants

	(O) Observed Frequency	(E) Expected Frequency*	(D) Difference	(O-E) ²	(O-E) ² /E
Head & Neck	4	5	-1	2	0.38
Lung	12	12	0	0	0
Breast	25	16	9	72	4.39
Liver	3	1	2	4	3.25
Pancreas	1	2	-1	0	0.23
Bladder	2	4	-2	4	1.06
Colorectal	11	7	4	18	2.73
Female Reproductive	6	8	-2	4	0.46
Male Reproductive	9	5	4	13	2.33
Blood	8	7	1	0	0.07
Skin	4	3	1	1	0.29

Note. Expected frequencies were calculated based on observed frequencies of cancer type among all new cancer cases at PRCP at the time this evaluation was conducted (see Appendix F for a full report, PRCP Incidence of Cancer by Site and Primary Payer Report).

For single-use participants, the mean stage was 2.56 (median = 3, mode = 4) with stage IV occurring most frequently. Similar to cancer type, because all patients receive psychosocial screening at PRPC and, therefore, presumably interact with PSS staff on at least one occasion, cancer stage was expected to be evenly distributed relative to PRCP patient demographics.

A chi-square analysis was conducted to determine if the distribution of cancer stage among single-use participants was meaningful compared to demographics of all new cancer cases. Results from the chi-square analysis suggested the distribution of single-use participants based on cancer stage was not due to chance alone ($\chi^2_{(3)} = 17.89, p < 0.05$). Indeed, single-use participants with stage IV cancer were represented far more frequently than statistically expected, while stages I–III were represented as expected compared to PRCP statistics.

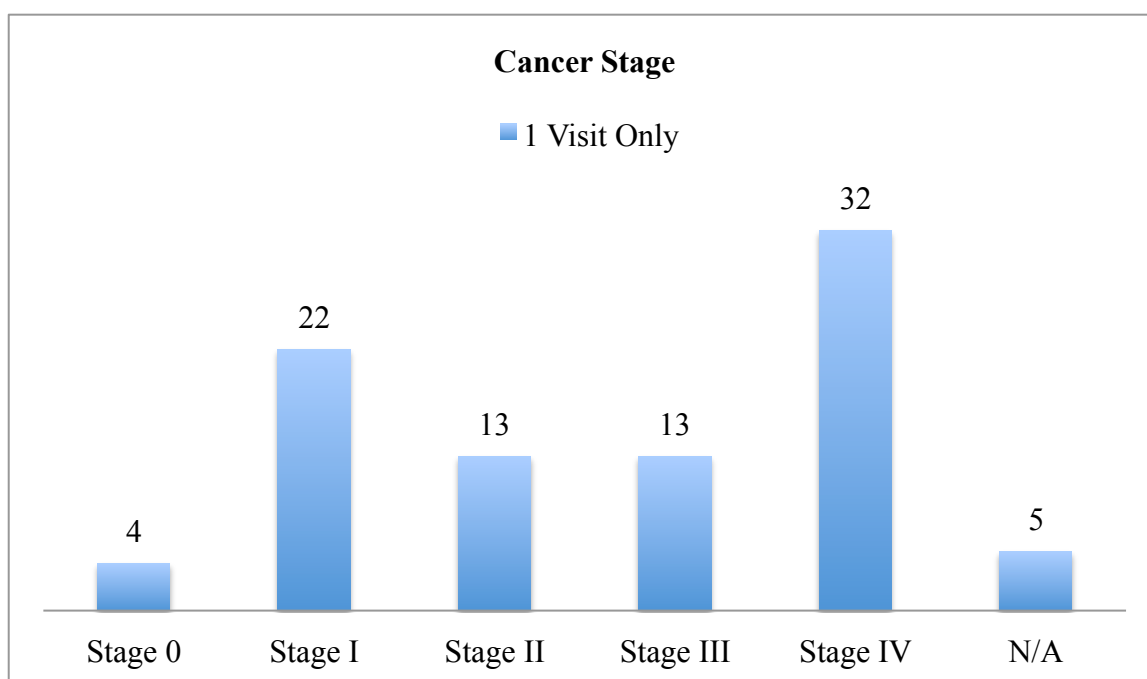


Figure 7. Distribution of cancer stage: single-use participants.

Table 7

Chi-Square Analysis: Cancer Stage Among Single-Use Participants

	(O) Observed Frequency	(E) Expected Frequency	(D) Difference	(O-E) ²	(O-E) ² /E
Stage I	22	24	-2	3	0.11
Stage II	13	14	-1	0	0.03
Stage III	13	10	3	10	1.01
Stage IV	32	16	16	264	16.73

The majority of single-use participants engaged in program services for the purpose of distress assessment ($n = 70$), which was extremely likely because all patients receive psychosocial distress screening as mandated by NCCN guidelines (2016b). Of note, 17% of single-use participants involved family members ($n = 15$). Minimal single-use or first time interactions with PSS occurred during infusion treatments ($n = 3$) or during office visits ($n = 7$), which likely reflected the way patient referrals were made to PSS and, thus, how patients were first introduced to program services.

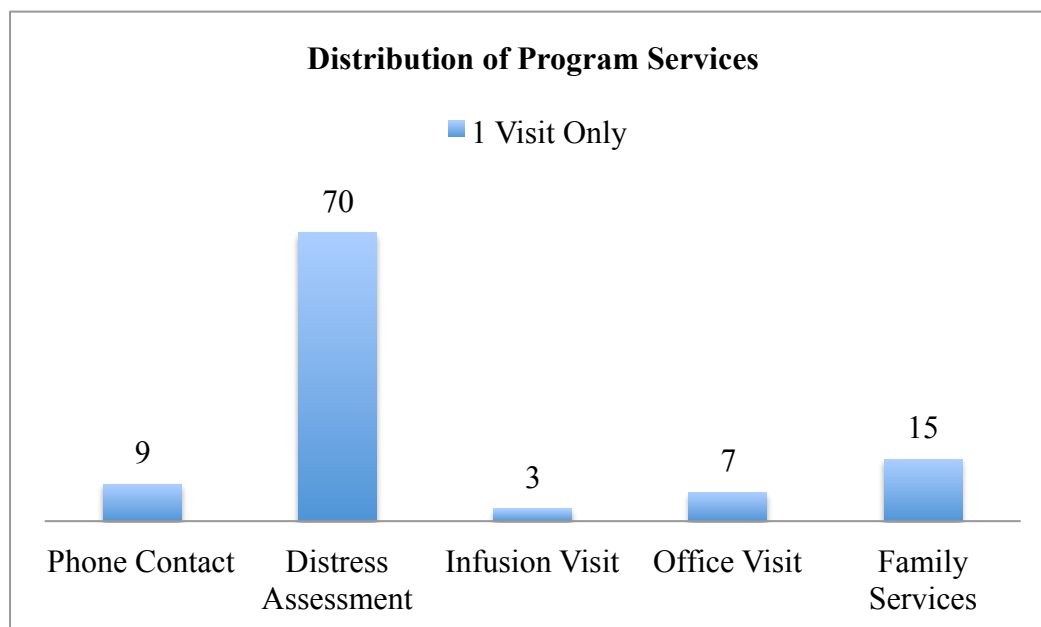


Figure 8. Distribution of program services: single-use participants.

Multiuse program participants. Two hundred and twelve participants used program services on more than one occasion. Thirty-six percent of multiuse participants were male, while 64% were female. The majority of multiuse participants were between the ages 55–64 ($n = 35\%$), representing a slightly younger patient demographic than single-use participants. The mean age was 61.4 (median = 61, mode = 62). Twenty-three percent of multiuse participants were ages 65–74, 20% were ages 45–53, and 16% were 75 or older. Fewer than 7% of multiuse participants were under the age of 45.

Table 8

Percentage Rates and Frequency of Demographics: Multiuse Participants

	Percentage	Frequency
Gender		
Male	36.3%	77
Female	63.7%	135
Participants Age		
18 to 25	0.5%	1
26 to 34	1.9%	4
35 to 44	4.2%	9
45 to 54	19.8%	42
55 to 64	35.4%	75
65 to 74	22.6%	48
75 or older	15.6%	33

Breast cancer patients were highly representative of multiuse participants, representing the majority of users ($n = 50$), which mirrored high prevalence rates of breast cancer among all new cancer cases at PRCP, in general. Lung cancer, which was second most prevalent among all new cancer cases at PRCP, was also well represented among multiuse participants ($n = 39$), as were head and neck ($n = 23$) and blood cancers ($n = 27$).

A chi-square analysis was conducted to determine if the distribution of cancer types among multiuse participants was equal to what would be expected relative to statistics of all

cancer cases treated at PRCP. Results from the chi-square analysis suggested the distribution of cancer types among multiuse participants was not due to chance ($X^2_{(12)} = 32.94, p < 0.05$), indicating differences between multiusers and PRCP's general patient population. Even when high prevalence rates were accounted for among all cancer cases, breast and lung cancer patients were still represented more frequently than expected when compared to PRCP's patient population. Additionally, head and neck, pancreatic, and blood cancers were represented more frequently among multiuse participants than predicted. Bladder cancer, on the other hand, was represented less frequently than expected. The remaining cancer types—glioblastomas, liver, kidney, colorectal, female and male reproductive cancer, and skin cancer—appeared to mirror expected prevalence rates.

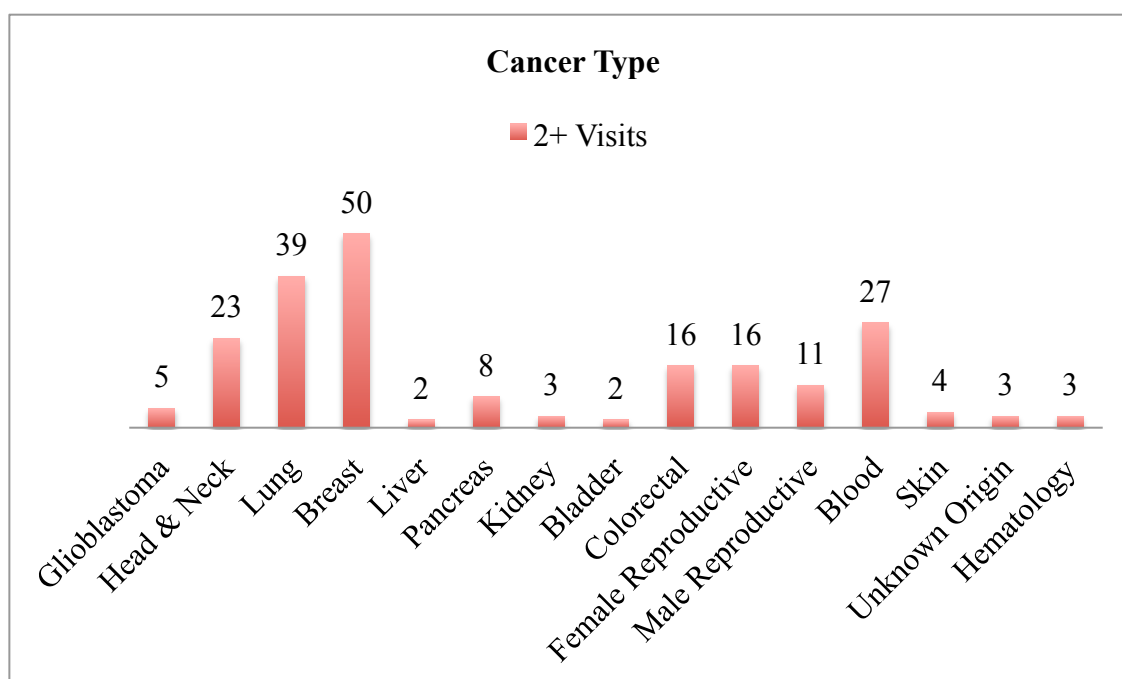


Figure 9. Distribution of cancer type: multiuse participants.

Table 9

Chi-Square Analysis: Cancer Type Among Multiuse Participants

	(O) Observed Frequency	(E) Expected Frequency*	(D) Difference	(O-E) ²	(O-E) ² /E
Glioblastoma	5	4	1	2	0.64
Head & Neck	23	13	10	96	7.31
Lung	39	30	9	87	2.94
Breast	50	40	10	101	2.52
Liver	2	3	-1	0	0.17
Pancreas	8	4	4	17	4.27
Kidney	3	6	-3	9	1.48
Bladder	2	10	-8	62	6.29
Colorectal	16	16	0	0	0
Female	16	19	-3	10	0.52
Reproductive					
Male	11	13	-2	5	0.36
Reproductive					
Blood	27	18	9	86	4.87
Skin	4	7	-3	12	1.57

Note. Expected frequencies were calculated based on observed frequencies of cancer type among all new cancer cases at PRCP at the time this evaluation was conducted (see Appendix

F for a full report, PRCP Incidence of Cancer by Site and Primary Payer Report).

Stage IV cancer was significantly more common among multiuse participants than earlier stage cancer ($n = 112$); the mean stage was 3.13 (median = 4, mode = 4). A chi-square analysis was conducted to determine if the distribution of cancer stages was meaningful or likely due chance compared to demographics of all new cancer cases at PRCP. Results from the chi-square analysis suggested the distribution of cancer stages among multiuse participants was not due to chance ($X^2_{(3)} = 149.90$, $p < 0.05$). As speculated, multiuse participants with stage IV cancer were represented more frequently than statistically expected. Despite comprising 19.7% of PRCP's entire patient population, stage IV cancer patients represented 52.8% of all multiuse participants. Alternately, participants with stage I cancer were significantly underrepresented. Stage I cancer patients comprised the majority of PRCP's patient population ($n = 29.5\%$), but only comprised 11.3% of multiuse participants.

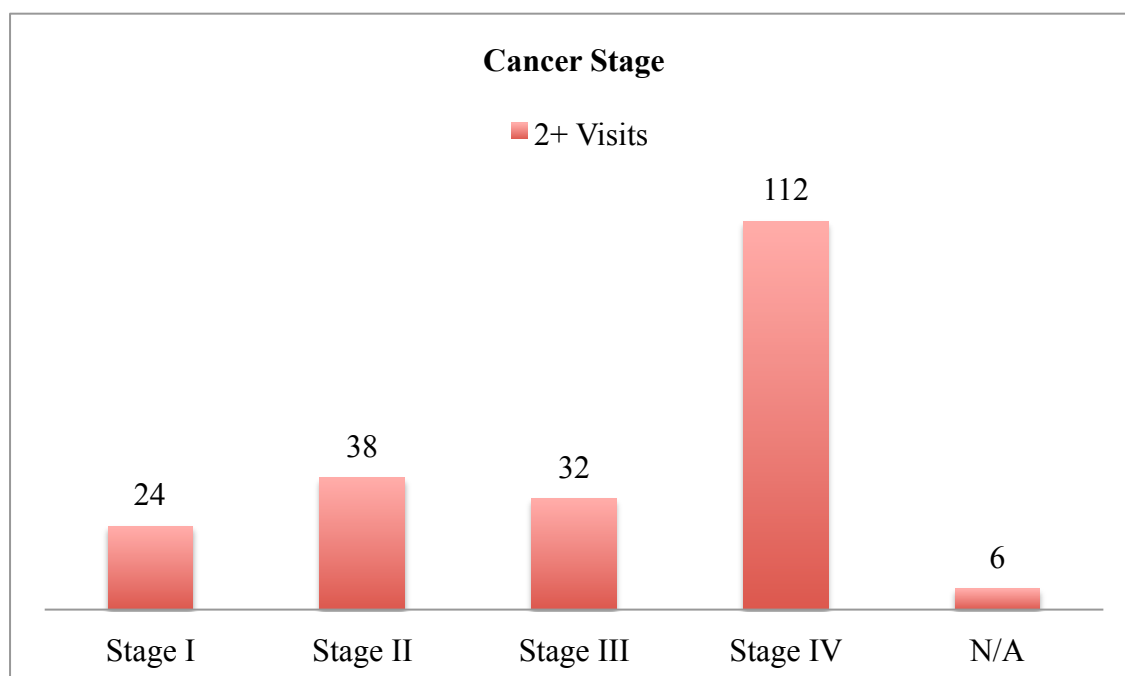


Figure 10. Distribution of cancer stage: multiuse participants.

Table 10

Chi-Square Analysis: Cancer Stage Among Multiuse Participants

	(O) Observed Frequency	(E) Expected Frequency	(D) Difference	(O-E) ²	(O-E) ² /E
Stage I	24	61	-37	1,352	22.25
Stage II	38	35	3	8	0.22
Stage III	32	25	7	44	1.75
Stage IV	112	41	71	5,101	125.68

The average number of visits or points of contact with PSS staff was 7.98 for multiuse participants (median = 4, mode = 2). An analysis of the frequency of contact with PSS based on participants' stage cancer illustrated that participants with advanced stage cancer were significantly more likely to have more frequent interaction with PSS than participants with early-stage cancer.

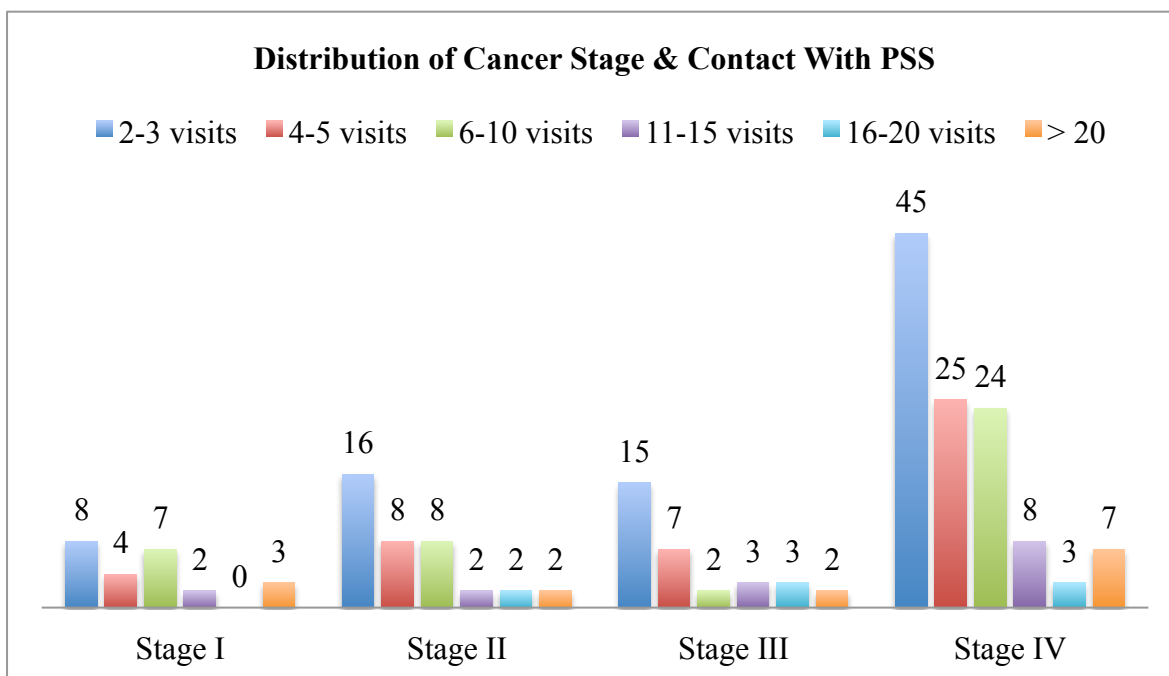


Figure 11. Distribution of cancer stage and contact with PSS: multiuse participants.

Beyond phone contact and distress assessment, multiuse participants utilized a range of program services. Participants were most likely to have interaction with staff at an office visit ($n = 82$) or during infusion treatment ($n = 81$). Of note, 42% of the multiuse participants involved family members in their care ($n = 88$). Multiuse participants also utilized nutrition services ($n = 69$) and the Cancer Resource Center ($n = 60$) on a fairly consistent basis; however, financial services were less likely to be utilized ($n = 34$).

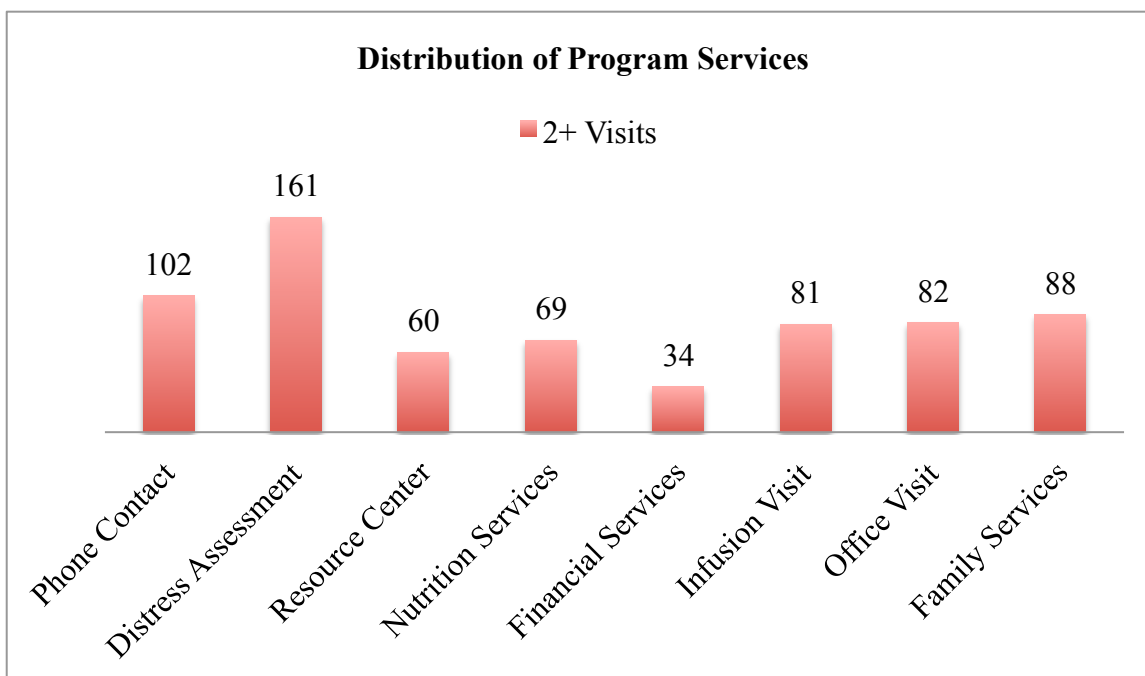


Figure 12. Distribution of program services: multiuse program participants.

Group program participants. Ninety-nine participants attended a support group on at least once occasion. Fifteen percent of group participants were male, while 85% were female. In general, group users were more likely to represent a younger patient population. The majority of group participants were between the ages 55–64 ($n = 32\%$) and the mean age was 57.7 (median = 57, mode = 52). Group users were most reflective of patients under the age of 45 ($n = 11\%$) compared to other participant groups and 29% of group participants were ages 45–54.

Table 11

Percentage Rates and Frequency of Demographics: Group Participants

	Percentage	Frequency
Gender		
Male	15.2%	15
Female	84.8%	84
Participants Age		
26 to 34	2.0%	2
35 to 44	9.1%	9
45 to 54	29.3%	29
55 to 64	32.3%	32
65 to 74	20.2%	20
75 or older	7.1%	7

While support groups presumably had the opportunity to reach a vast and broad population, the majority of group participants represented women diagnosed with breast cancer ($n = 64$). The fact that women with breast cancer dominated all other group participants was likely a result of the current content of support groups offered at PRCP. At the time of this evaluation, two of the six support groups facilitated at by PSS staff were exclusive to women diagnosed with breast cancer, clearly affecting group membership and representation. The remaining 35 participants represented a diverse set of cancers, though many cancers were underrepresented among group users. Lung and blood cancers were especially underrepresented compared to their prevalence among PRCP's general patient population. Results from a chi-square analysis confirmed the uneven distribution of cancer types among group members when compared to PRCP's patient population ($X^2_{(10)} = 116.67, p < 0.05$).

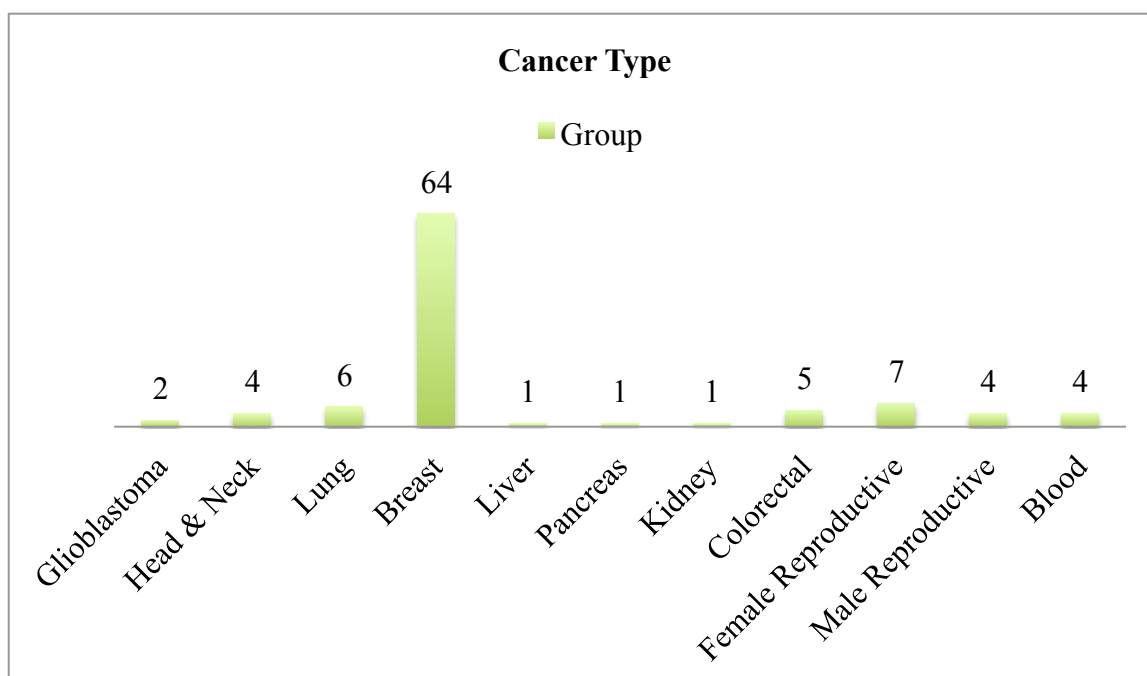


Figure 13. Distribution of cancer type: group participants.

Table 12

Chi-Square Analysis: Cancer Type Among Group Participants

	(O) Observed Frequency	(E) Expected Frequency*	(D) Difference	(O-E) ²	(O-E) ² /E
Glioblastoma	2	2	0	0	0
Head & Neck	4	6	2	5	0.86
Lung	6	14	8	68	4.78
Breast	64	19	-45	2,007	104.47
Liver	1	1	0	0	0
Pancreas	1	2	1	1	1
Kidney	1	3	2	4	1.22
Colorectal	5	8	3	8	1.02
Female Reproductive	7	9	2	5	0.53
Male Reproductive	4	6	2	5	0.86
Blood	4	9	5	20	2.39

Note. Expected frequencies were calculated based on observed frequencies of cancer type among all new cancer cases at PRCP at the time this evaluation was conducted (see Appendix F for a full report, PRCP Incidence of Cancer by Site and Primary Payer Report).

Contrary to multiuse participants, stage I cancer was more common among group participants than later stages of cancer ($n = 33$). The mean stage for group users was 2.16 (median = 2, mode = 1). A chi-square analysis was conducted to determine if the distribution of cancer stages was meaningful or likely due chance compared to demographics of all new cancer cases. Results from the chi-square analysis suggested the distribution of cancer stages among group participants was, in fact, equal to chance and reflective of PRCP's general patient population ($X^2_{(3)} = 7.84$).

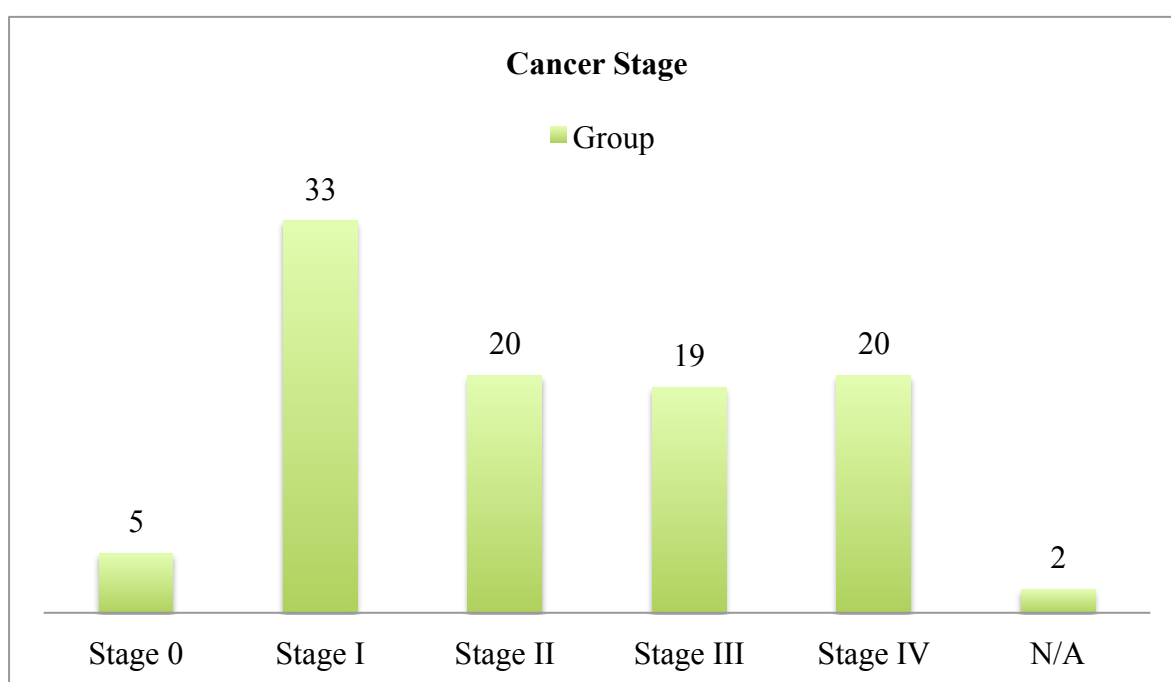


Figure 14. Distribution of cancer stage: group participants.

Table 13

Chi-Square Analysis: Cancer Stage Among Group Participants

	(O) Observed Frequency	(E) Expected Frequency	(D) Difference	(O-E) ²	(O-E) ² /E
Stage I	33	27	6	34	1.27
Stage II	20	16	4	18	1.58
Stage III	19	11	8	59	5.22
Stage IV	20	18	2	4	0.19

Figure 15 reflects the frequency of contact group participants had with PSS based on their stage cancer; contact frequency did not include the number of support groups attended by participants, only that a participant attended a support group and whether or not additional program services were used. The average number of visits or points of contact with PSS staff (not including number of support groups attended) was 10.37, suggesting that group participants use program services more frequently than other participants. Participants with early-stage cancer were more likely to only attend a support group and utilized fewer follow up visits than participants with cancer stages II–IV. Participants with later stage cancer (II–IV) appeared to utilize services fairly homogenously, demonstrating, again, the likelihood that the demographics of participants who attended groups was due to chance rather than representative of a meaningful difference.

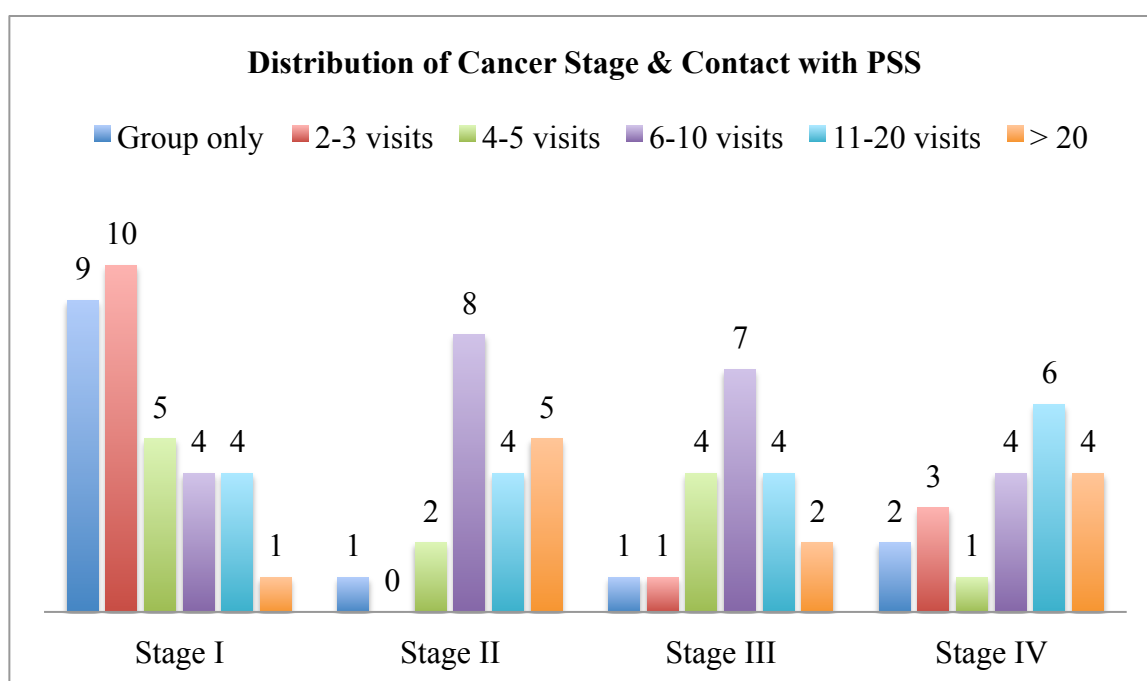


Figure 15. Distribution of cancer stage and contact with PSS: group participants.

Beyond phone contact and distress assessment, group participants were most likely to attend an office visit with PSS staff ($n = 51$). Of note, more than a third of group participants included family members in their care ($n = 37$), which may in part be attributed to support group options available to family members and caregivers. Group participants were more likely to utilize the Cancer Resource Center ($n = 35$), than receive support during infusion ($n = 26$). Nutrition and financial services were less likely to be utilized.

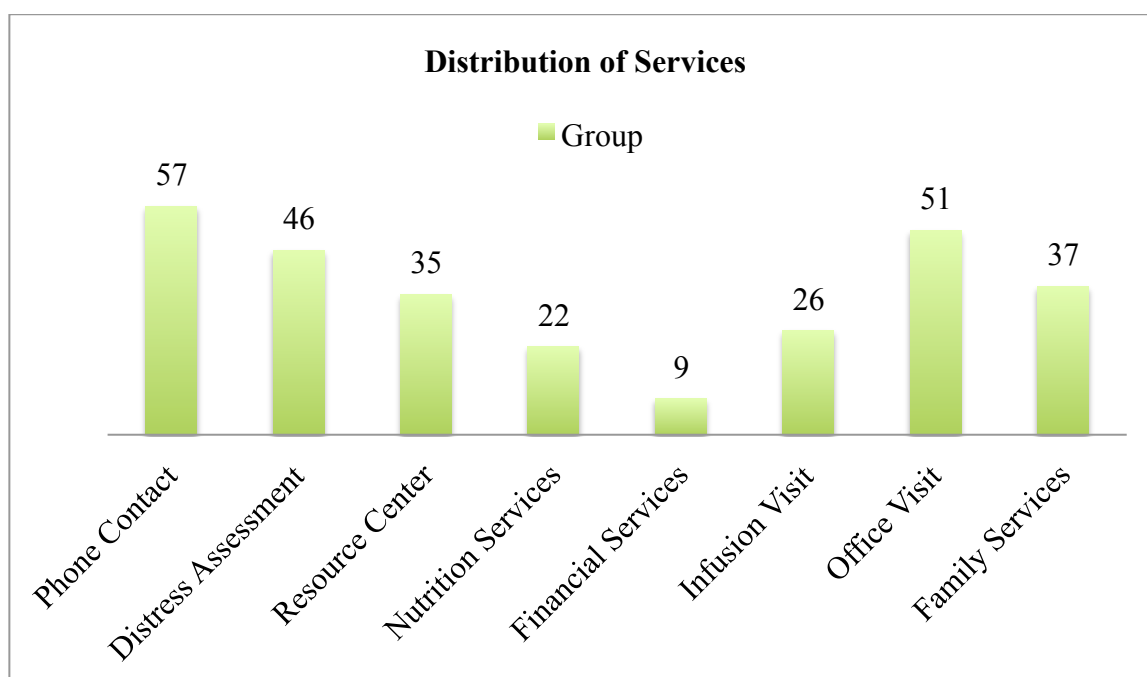


Figure 16. Distribution of program services: group participants.

Six support groups were offered to participants during the twelve months prior to this evaluation: general support (previously its own group, but now incorporative of the advanced cancer and caregiver support groups), tai chi, breast cancer, young women with breast cancer, art therapy, and survivorship. Figure 17 illustrates the number of new patients or family members that attended each support group on at least one occasion in the twelve months prior to this evaluation, as indicated by group sign in sheets. Aside from the survivorship group, support groups were similarly attended by participants, which included family members and patients of

other cancer facilities. The most frequently attended groups were tai chi ($n = 41$) and art therapy ($n = 41$). The third most frequently attended group was the general support group ($n = 34$). Of note, tai chi, art therapy, and the general support group were open to family members and caregivers of patients, which likely contributed to their more robust attendance numbers. The two breast cancer support groups were limited to patients or survivors of breast cancer. The survivorship support group was the only closed group offered at PRCP, requiring preregistration and occurring on a more limited basis, reflecting its smaller attendance numbers.

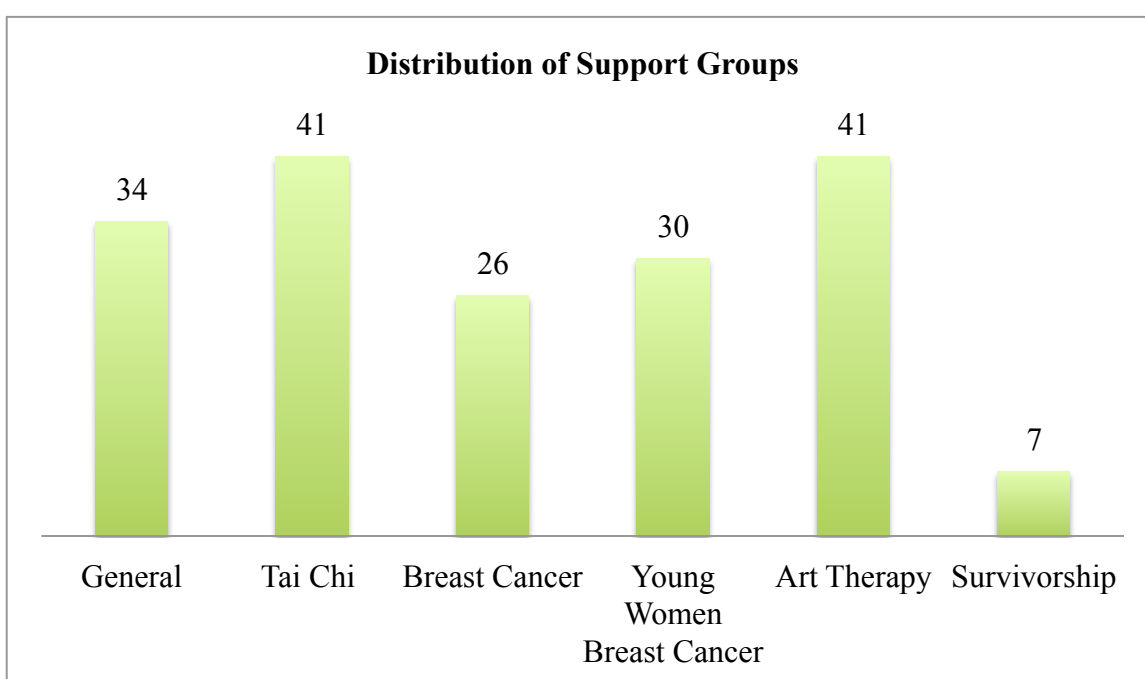


Figure 17. Distribution of support groups: group participants.

Comparison of program services between group categories. After reviewing patient demographics for single-use, multiuse, and group participants separately, data was again aggregated to compare how program services were utilized between the three participant groups.

Multiuse and group participants were most likely to represent patients 55–64 years old, whereas single-use participants were most likely to represent patients over the age of 65. Single-use participants were especially representative of patients older than 75, compared to multiuse

and group participants. Group participants were observed in high numbers among patients age 45–54 compared to single and multiuse participants. Patients under the age of 44 were represented across all three groups nearly equally, with patients age 35–44 represented more frequently observed in groups than among single or multi-service users.

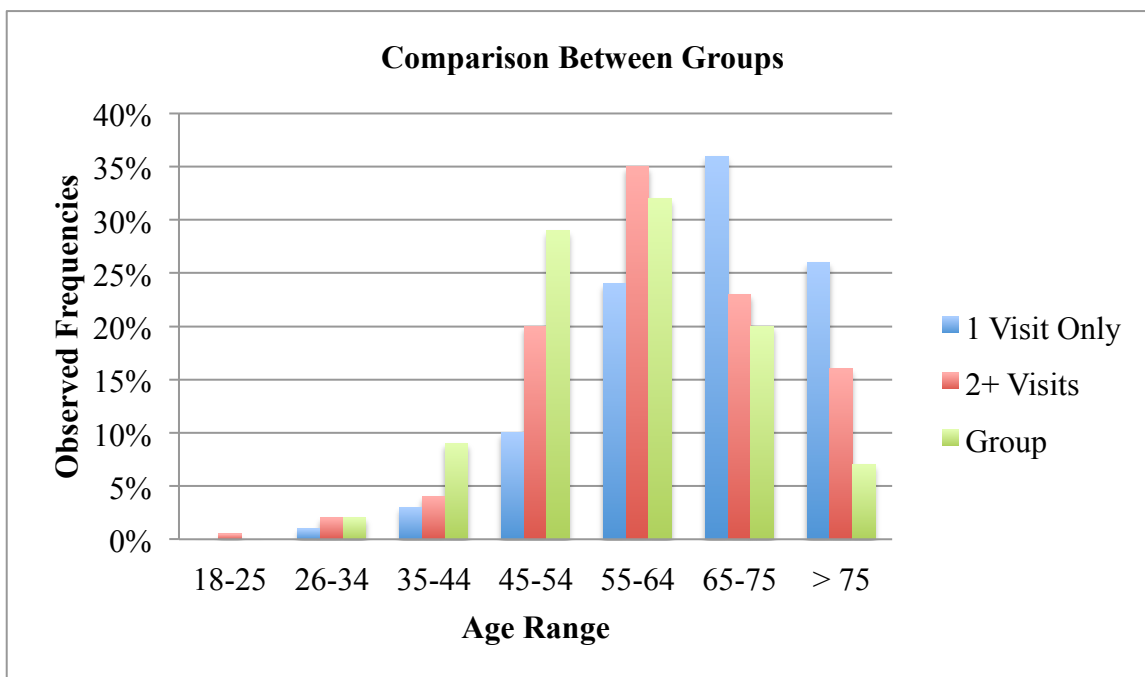


Figure 18. Comparison between groups: age range.

Figure 19 illustrates how PSS services were utilized by age range. Aside from telephone contact and distress assessments which should capture most of all patients based on NCCN (2016b) psychosocial screening guidelines, several program services stand out among participants, regardless of age. Infusion, office visits, support groups, and family counseling were well utilized by all participants to a large degree, regardless of age. Financial support, the Cancer Resource Center, and nutrition services appeared to be less well utilized than counseling services.

Participants 55–64 years old were most frequently and consistently represented across all program services, followed by participants ages 45–54. Participants under the age of 35 were

consistently underrepresented across all program services, which was indicative of lower cancer incidence rates of younger persons in general (Cancer Research UK, 2016) and PRCP's patient population at-large. Participants over the age of 75 were less likely to engage in program services beyond distress assessment; however, elderly participants did commonly involve family members in their care, respective of their overall participation in program services.

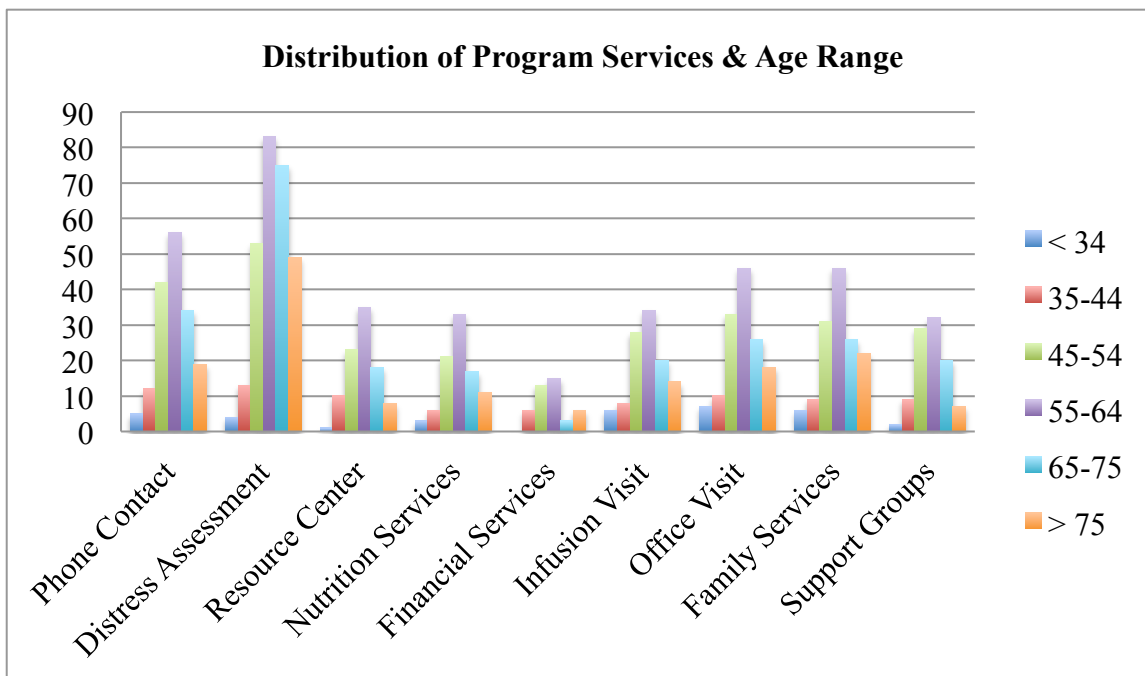


Figure 19. Distribution of program services: age range.

Women were more frequently represented in higher numbers across all three groups, representing 68% of all participants ($n = 271$). Men and women were most evenly distributed among single-use participants, which was likely due to the fact that all patients receive at least an initial, one-time screening with PSS staff whereas group and multiuse participants represented patients seeking follow up care beyond an initial screening. It appeared that, in general, men were much less likely to seek services beyond an initial screening.

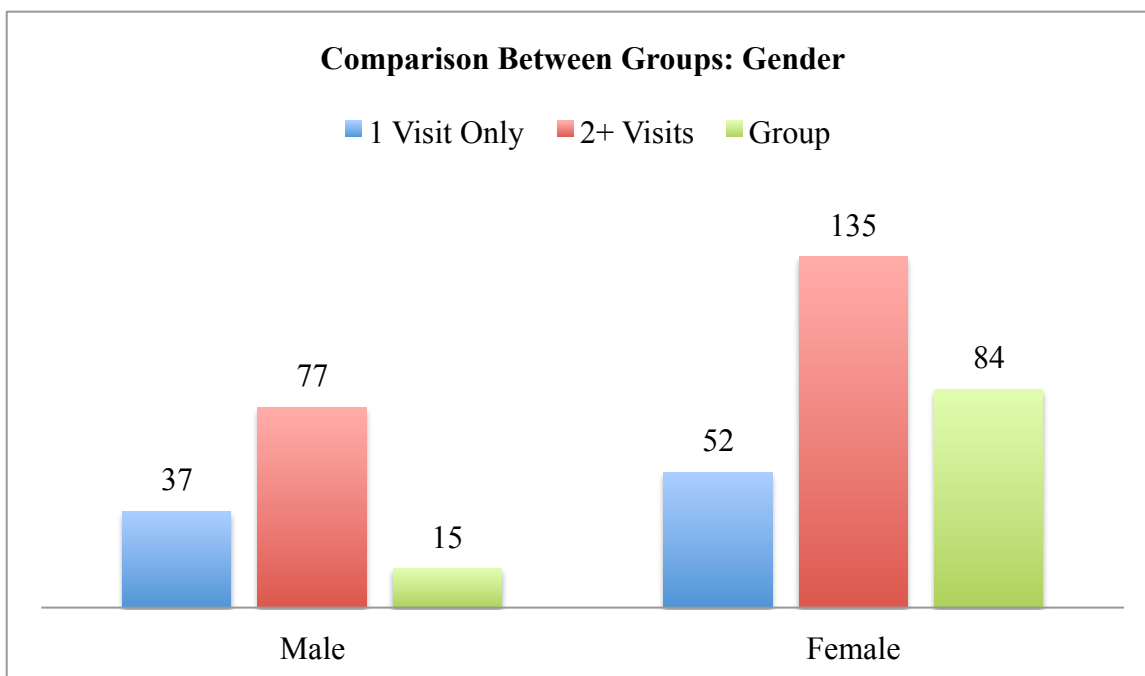


Figure 20. Comparison between groups: gender.

Women were consistently represented in higher numbers across all program services. Women were least likely to utilize financial services, representing fewer than 11% of all female participants. Women were consistently represented among the Cancer Resource Center, infusion, office visits, family counseling, and support groups, with the highest percentage of women attending an office visit ($n = 35\%$).

Men appeared less likely to utilize supplemental supportive services, such as the Cancer Resource Center or financial support. Men were also poorly represented among support groups, although the current data did not include information from the men's only support group for prostate cancer because PSS staff did not facilitate that group. Forty-four percent of men did, however, include family members in their care and 35% of men attended an office visit with staff. Support during infusion and nutrition services were utilized by 27–29% of male participants, respectively.

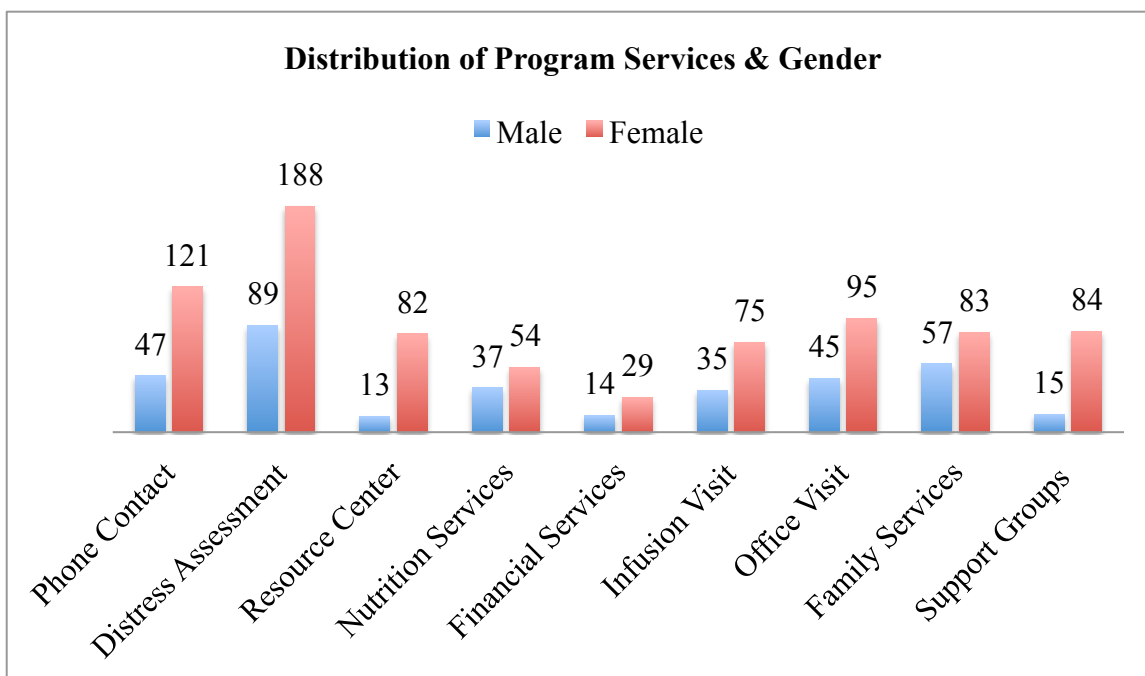


Figure 21. Distribution of program services: gender.

Participation in program services appeared to vary based on participants' primary health insurance coverage. In general, participants with Medicaid were more likely to participate in nearly all program services, despite comprising only 16% of all participants. Especially noteworthy, participants with Medicaid were three times as likely to utilize financial services ($n = 27\%$) compared to Medicare ($n = 9\%$) and commercial insurance users ($n = 5\%$).

Commercial and Medicare participants appeared nearly unequivocal across all program services, aside from distress assessment and support groups. Medicare participants were more likely to receive follow up on distress assessments while participants with commercial insurance were nearly twice as likely (36%) to participate in support groups than either Medicare ($n = 16\%$) or Medicaid ($n = 17\%$) participants.

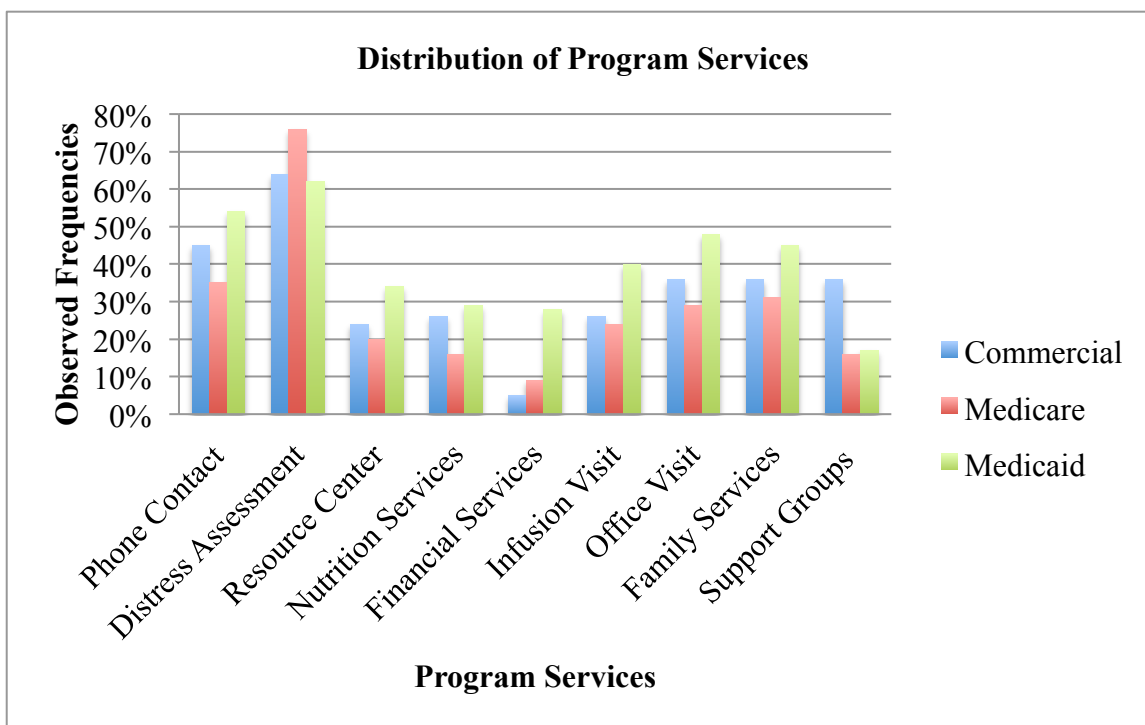


Figure 22. Distribution of program services: primary insurance.

Figure 23 illustrates how cancer diagnoses varied among service user groups. As previously discussed, breast cancer patients represented the majority of PRCP's patient population at-large. As such, breast cancer patients were more frequently represented across all three groups by a significant amount, nearly one and a half times the frequency of all other single and multiuse participants and nearly ten times the frequency of all other group participants. Further, breast cancer patients were nearly three times as likely to attend a support group than to represent single or multi-use participants.

Because breast cancer patients dominated the representation of group program users, differences could be seen among group users and single/multiuse participants across cancer type. For example, lung cancer patients were three times as likely to represent multiuse participants

($n = 18$) than group participants ($n = 6$). Likewise, patients with blood cancer were also three times as likely to represent multiuse participants ($n = 13$) than group participants ($n = 4$). Head and neck cancer patients were more than two times as likely to represent multiuse participants ($n = 11$) than single-use and group participants ($n = 4$). In a few instances, single-use participants outnumbered multiuse and group participants, as was the case with colorectal and male reproductive cancer patients. Interestingly, patients with female reproductive cancers were represented nearly homogenously across participant groups.

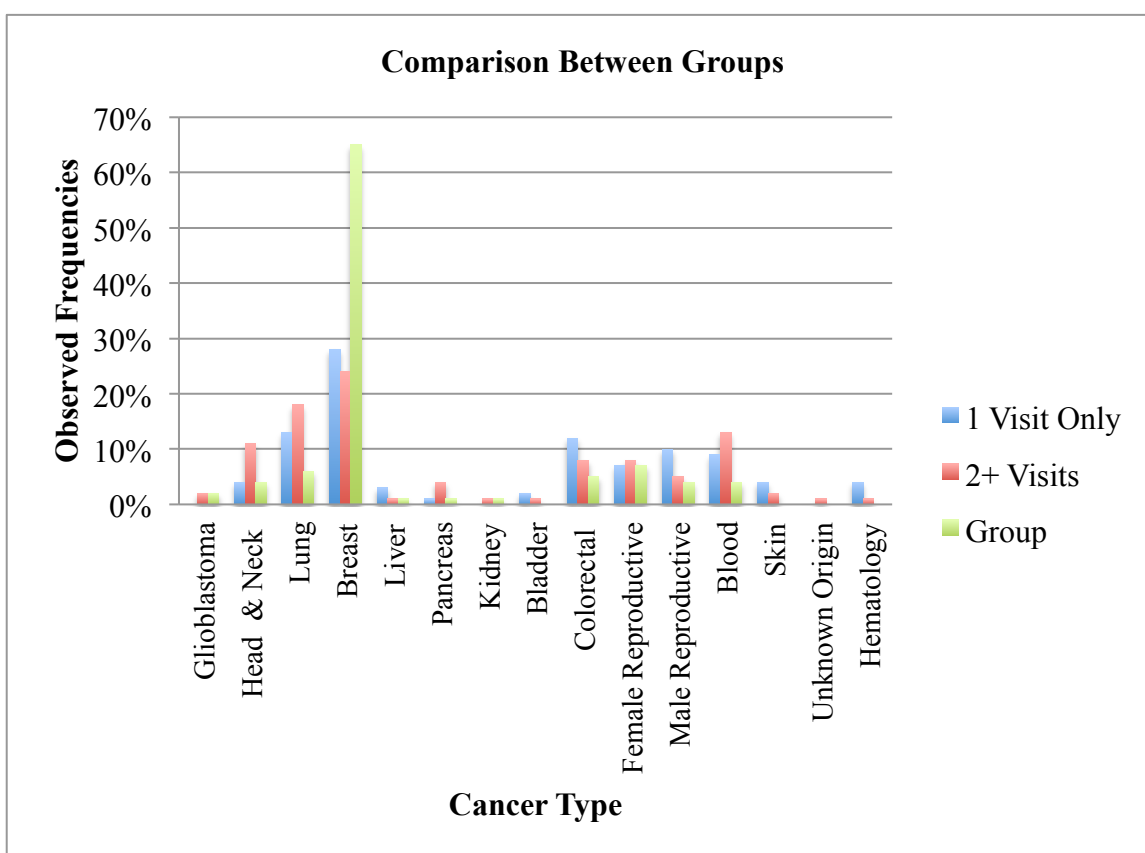


Figure 23. Comparison between groups: cancer type.

Figure 24 reflects how program services were utilized across common cancer diagnoses. Breast cancer was superiorly represented across all program services, which corresponds with high prevalence rates ($N = 12.3\%$) observed nationally (National Cancer Institute, 2016) and

among PRCP's patient population ($n = 22.6\%$). Participants with breast cancer were most well represented in support groups ($n = 64$) in addition to office visits ($n = 52$). Interestingly, despite similarly high prevalence rates for prostate cancer ($N = 14\%$), participants with male reproductive cancers were consistently represented in low numbers across program services and within PRCP in general. Of the male reproductive cancer patients that did utilize program services, participants were most likely to involve family members in their care ($n = 9$) and least likely to utilize financial services ($n = 0$).

Lung cancer, which represents 13.3% of all new expected cancers nationally, was the second most commonly occurring cancer at PRCP and, similarly, the second most prominent cancer represented across program services unanimously. Participants with lung cancer were especially well represented among family counseling services ($n = 22$) and less likely to utilize financial services ($n = 4$) or support groups ($n = 5$).

Participants with head and neck, colorectal, female reproductive, and blood cancer were closely represented across program services. Notably, participants with head and neck cancer were most likely to utilize nutrition services ($n = 21$), which was likely due to adverse effects from treatment commonly associated with head and neck cancer patients (National Cancer Institute, 2013).

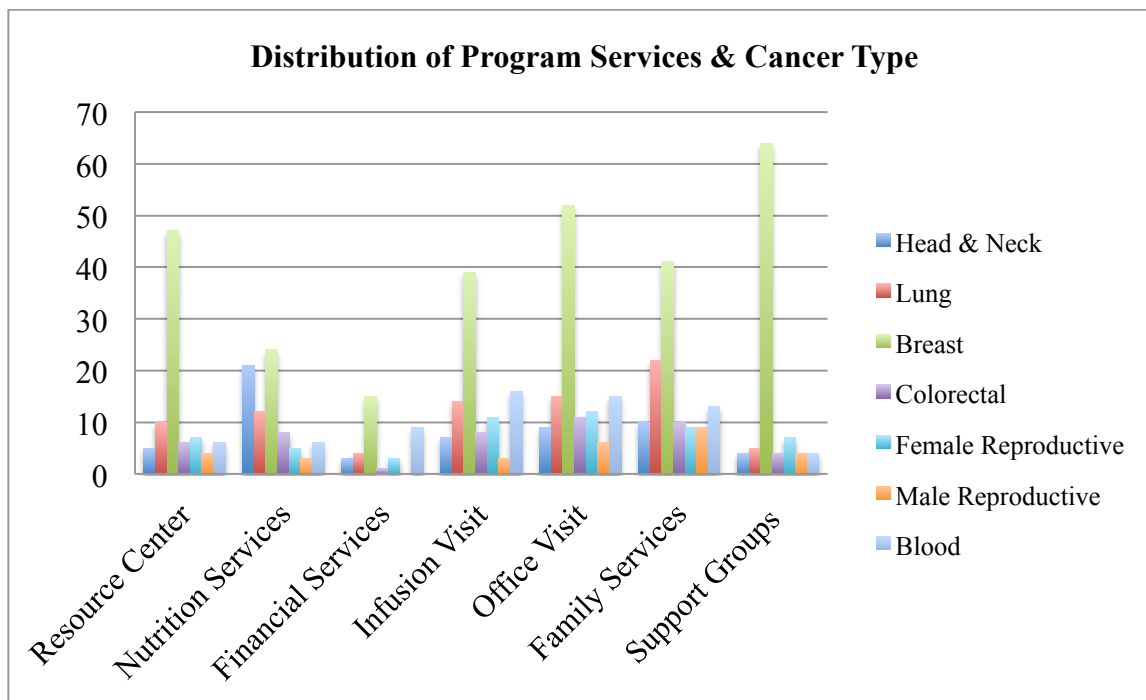


Figure 24. Distribution of program services: cancer type.

As previously demonstrated in Figures 6 and 9, patients with stage IV cancer were most well represented among single and multiuse participants, with the highest percentage of stage IV patients representing multi service users ($n = 53\%$). Alternately, stage I patients were most likely to represent group participants.

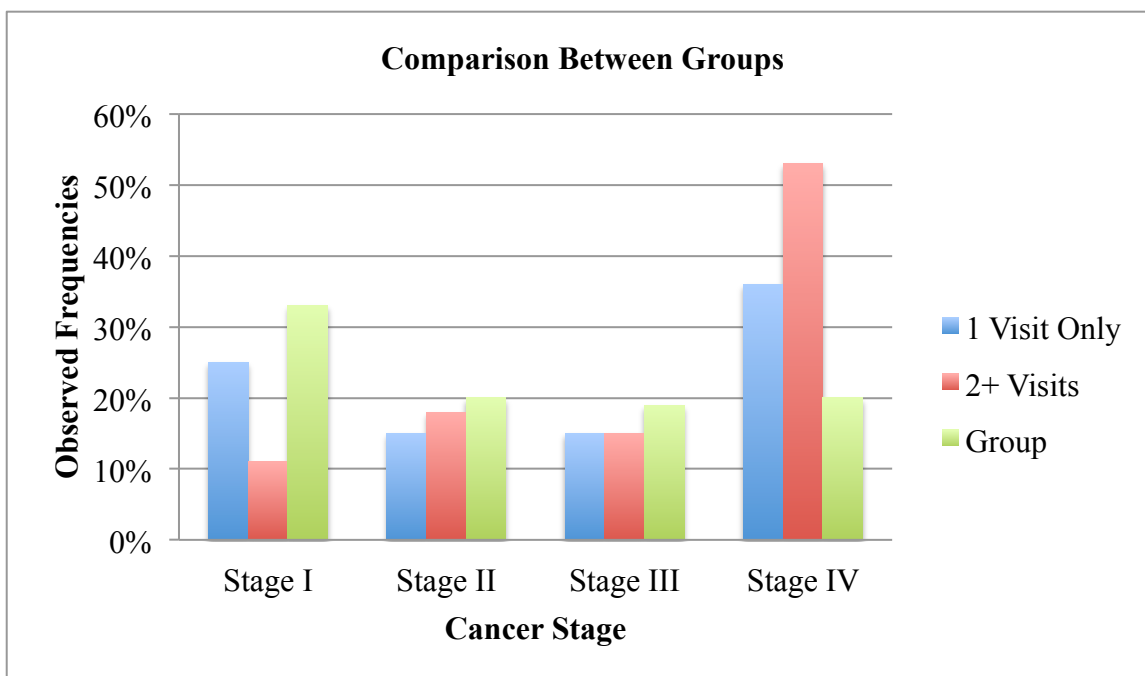


Figure 25. Comparison between groups: cancer stage.

Patients with stage IV cancer were represented more frequently than earlier stage cancer across all program services, with the exception of support groups. Patients with stage IV cancer were nearly three times as likely to involve family members in their care and two times as likely to attend an office visit, receive services during infusion, and participate in nutrition services. Alternately, patients with stage I cancer were represented less frequently across all program services, with the exception of support groups in which case patients with stage I cancer were most commonly observed ($n = 33$). Patients participated in the Cancer Resource Center nearly equally, while financial services were most frequently utilized by patients with cancer stage II and later.

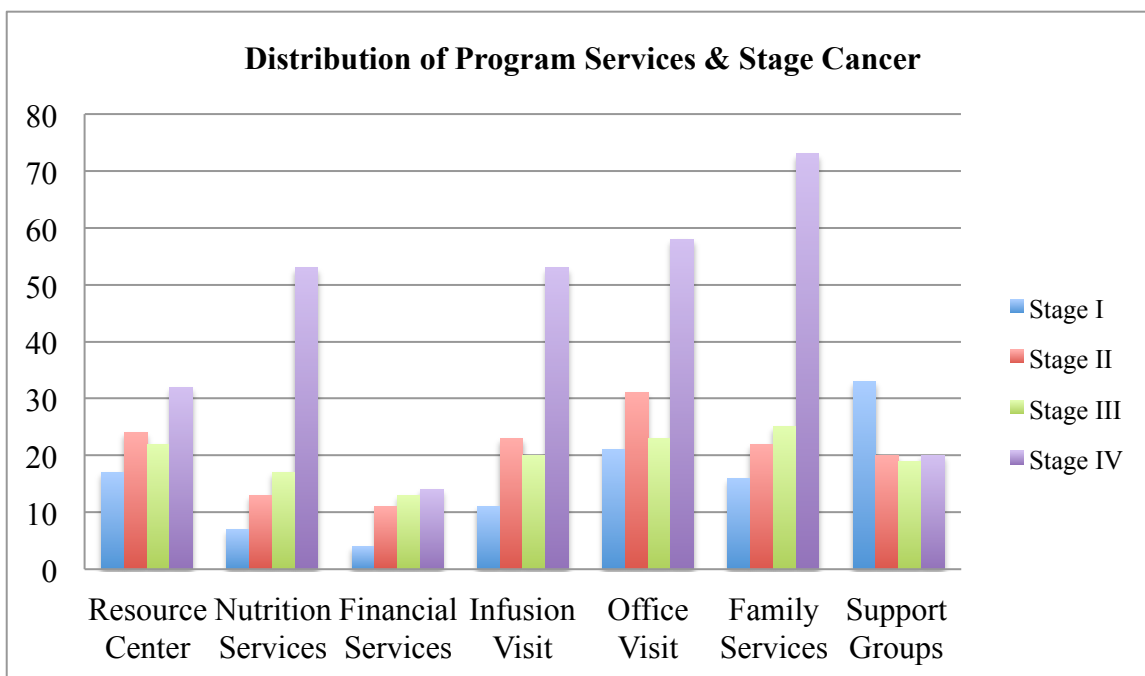


Figure 26. Distribution of program services: cancer stage.

Patients receiving chemotherapy were represented in high numbers across most program services, which could be expected given the near ubiquity of chemotherapy in treating cancer systemically (Cancer Research UK, 2015). Interestingly, patients who received chemotherapy alone were most likely to attend an office visit ($n = 35$) and involve family members in their care ($n = 39$), even more so than patients receiving chemotherapy in addition to surgery and/or radiation. Patients receiving radiation alone were also more likely to involve family members than patients receiving multiple treatments ($n = 31$).

Of note, patients receiving multiple treatments (surgery + chemotherapy, surgery + chemotherapy + radiation) were nearly twice as likely to attend a support group than patients receiving surgery, chemotherapy, or radiation alone. Patients receiving multiple treatments were also more likely to use the Cancer Resource Center than patients receiving single modality treatments. Financial services were utilized fairly evenly among participants, though patients

receiving radiation or surgery combined with chemotherapy were less likely to use financial services than others.

Differences in how program services were utilized may be, in part, attributed to how program referrals were made within each department, as distinct departments govern surgery, chemotherapy, and radiation and referrals were likely handled differently between each department. Additionally, differences in program participation may have been indicative of how patients' needs and their ability to utilize program services fluctuated as they moved throughout the treatment process.

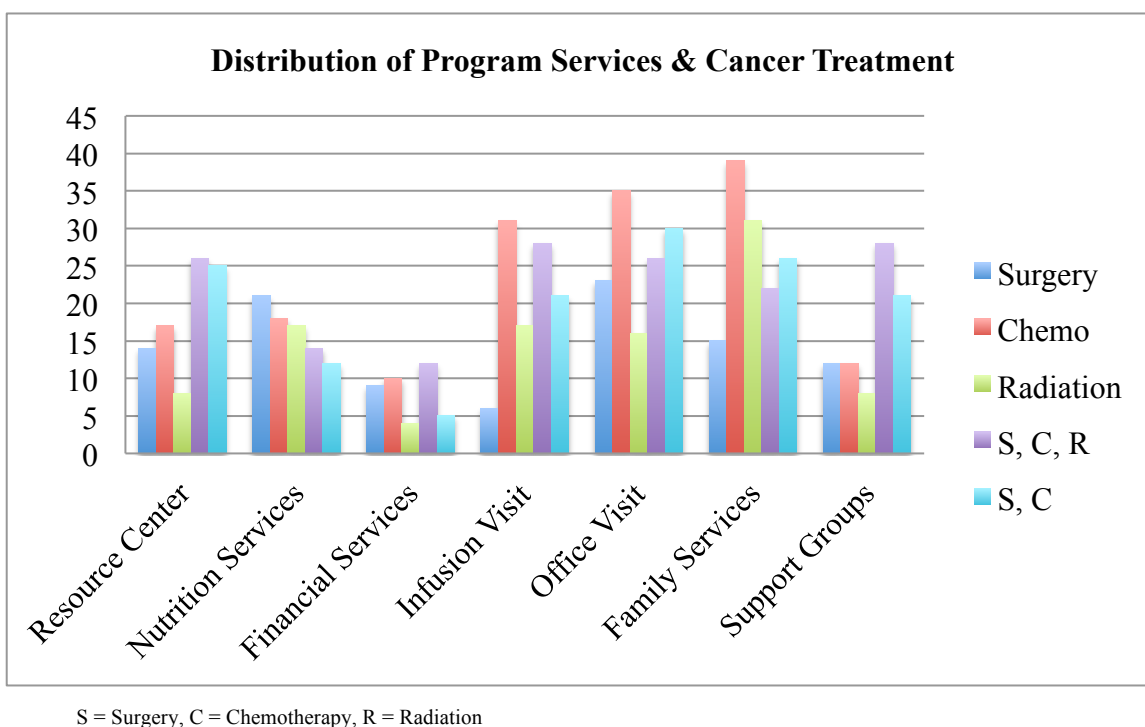


Figure 27. Distribution of program services: cancer treatment.

Satisfaction of Services

Two surveys were created and distributed to patients and PRCP staff to solicit feedback and opinions about their experiences using PSS program services. Patients and PRCP staff were asked to respond to a series of statements indicating their level of agreement or disagreement.

Statements inquired about patients' familiarity with the department and program services, utilization of services, satisfaction with the quality and variety of program services and PSS staffing, opinions about the impact program services had as part of their cancer care treatment, and perceived strengths and areas for improvement. Similarly, PRCP staff were asked about their familiarity with the department and program services, the referral process (how often, which services, and under what circumstances program services were recommended), opinions about the importance or value including behavioral health services in a cancer treatment program, and perceived strengths and areas for improvement. Results from surveys were used to identify trends and inform program recommendations based on perceived strength and areas of improvement.

Patient satisfaction. In total, 590 surveys were made available for distribution to patients by mail ($n = 440$) and in person ($n = 150$). One hundred and fifty-two patient surveys were returned, accounting for a 26% return rate. Seventy-nine surveys were returned by mail, 49 surveys were returned to reception following office visits with an oncologist, 18 surveys were returned to American Cancer Society volunteers during chemotherapy infusion, and six surveys were returned to PSS staff following a support group meeting.

Patient demographics. Demographic information was collected to describe the patient population who participated in providing program feedback. Of the 152 returned surveys, 142 surveys were completed by patients and nine were completed by family members or caregivers. The majority of respondents were between the ages 65–74 ($n = 56$). Fewest responses were received from persons under the age of 45 ($n = 7$).

Sixty-two percent of respondents identified as female and 38% identified as male. The majority of respondents identified as married or in a domestic partnership ($n = 89$), while 41%

identified as single ($n = 17$), separated ($n = 3$), divorced ($n = 18$), or widowed ($n = 14$). Ninety-one percent of respondents identified as Caucasian or White American while 9% identified as persons of color.

Table 14

Percentage Rates and Frequency of Patient Demographics

	Percentage	Frequency
Gender*		
Male	38.0%	57
Female	62.0%	93
Respondents Age**		
26 to 34	2.0%	3
35 to 44	2.7%	4
45 to 54	15.4%	23
55 to 64	21.5%	32
65 to 74	37.6%	56
75 or older	20.8%	31
Relationship Status*		
Single	11.3%	17
Married or Domestic Partner	59.3%	89
Separated	2.0%	3
Divorced	18.0%	27
Widowed	9.3%	14
Race/Ethnicity**		
Caucasian/White	90.7%	136
Hispanic/Latino	2.0%	3
African American/Black	0.7%	1
Asian/Pacific Islander	4.7%	7
American Indian/Alaska Native	2.0%	3

Note. *Based on 150 responses; two blank responses. **Based on 149 responses; three blank responses.

Cancer and treatment. Patient demographics were widely represented according to type and stage of cancer, the year treatment began, and types of treatment completed in the past twelve months. The majority of patients began treatment between 2014–2015 ($n = 97$); 24 patients began treatment between 2010–2013. Two patients began treatment prior to 2007, the

year PRCP was established as an integrative oncology center. Twenty-eight respondents did not report the year treatment began.

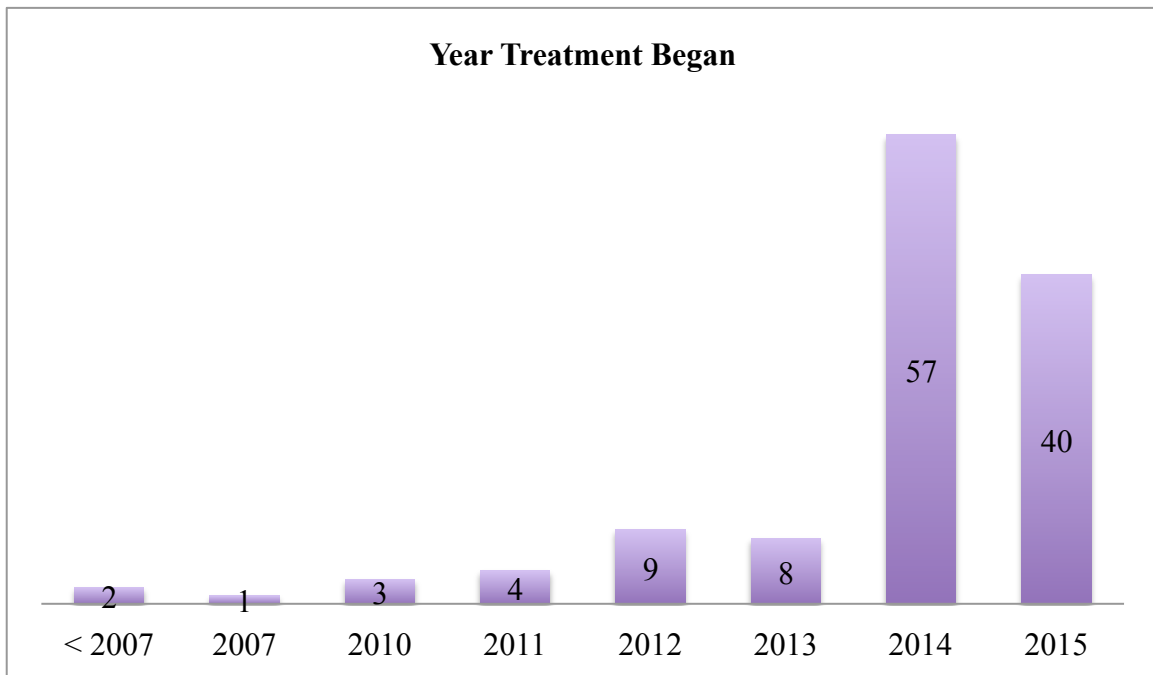


Figure 28. Patient demographics: year treatment began.

Among survey respondents, the three most frequently reported types of cancer were breast cancer ($n = 52$), blood cancer ($n = 21$), and male reproductive cancer ($n = 19$), representing 62% of all respondents. Female reproductive cancers and lung cancer were equally represented as the 4th and 5th most commonly occurring cancers among survey respondents, comprising 22% of all respondents.

Table 15

Percentage Rates and Frequency of Primary Cancer

What Type of Cancer is Being Treated?	Percentage	Frequency
Bladder cancer	1.4%	2
Blood cancer	14.2%	21
Bone cancer	3.4%	5
Brain tumor	3.4%	5
Breast cancer	35.1%	52
Colorectal cancer	7.4%	11
Female reproductive cancer	10.8%	16
Head and neck cancer	7.4%	11
Kidney cancer	0.7%	1
Liver cancer	2.7%	4
Lung cancer	10.8%	16
Male reproductive cancer	12.8%	19
Myelodysplastic syndrome	0.7%	1
Pancreatic cancer	1.4%	2
Skin cancer	2.0%	3
Soft tissue sarcoma	1.4%	2

Note. Based on 148 responses; four blank responses.

The demographics of survey respondents were compared to PRCP's population at-large. As evidenced in Figure 29, demographics of survey respondents were generally representative of PRCP's population at-large. Interestingly, the three most reported cancer types—breast, blood cancer, and male reproductive cancers—were overrepresented in the survey sample compared to PRCP's general population. Alternately, lung and bladder cancers appeared to be underrepresented in the survey sample compared to PRCP's population.

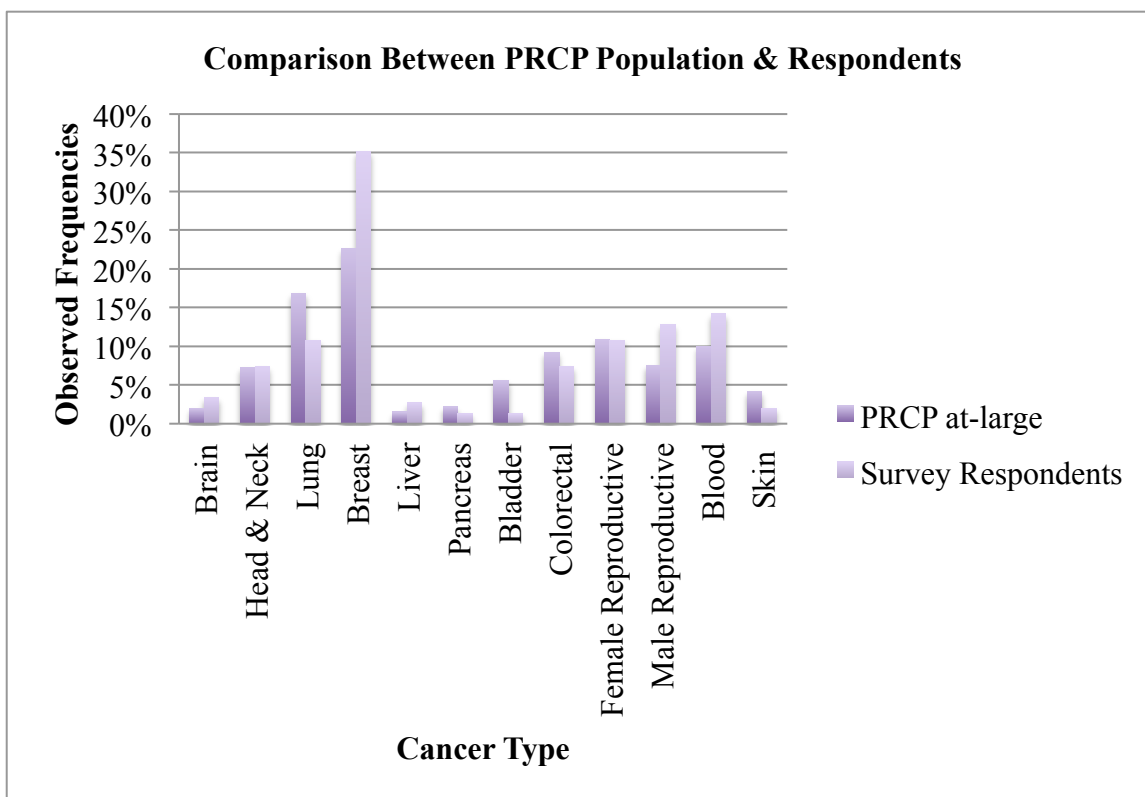


Figure 29. Comparison between PRCP population and survey respondents: cancer type.

A large percentage of respondents were unable to identify their stage of cancer ($n = 50$). Of those able and willing to report their stage of cancer, 28% of respondents identified as having stage IV disease, while only 14% of respondents reported stage I disease. Stages II and III cancer accounted for 27% of all respondents.

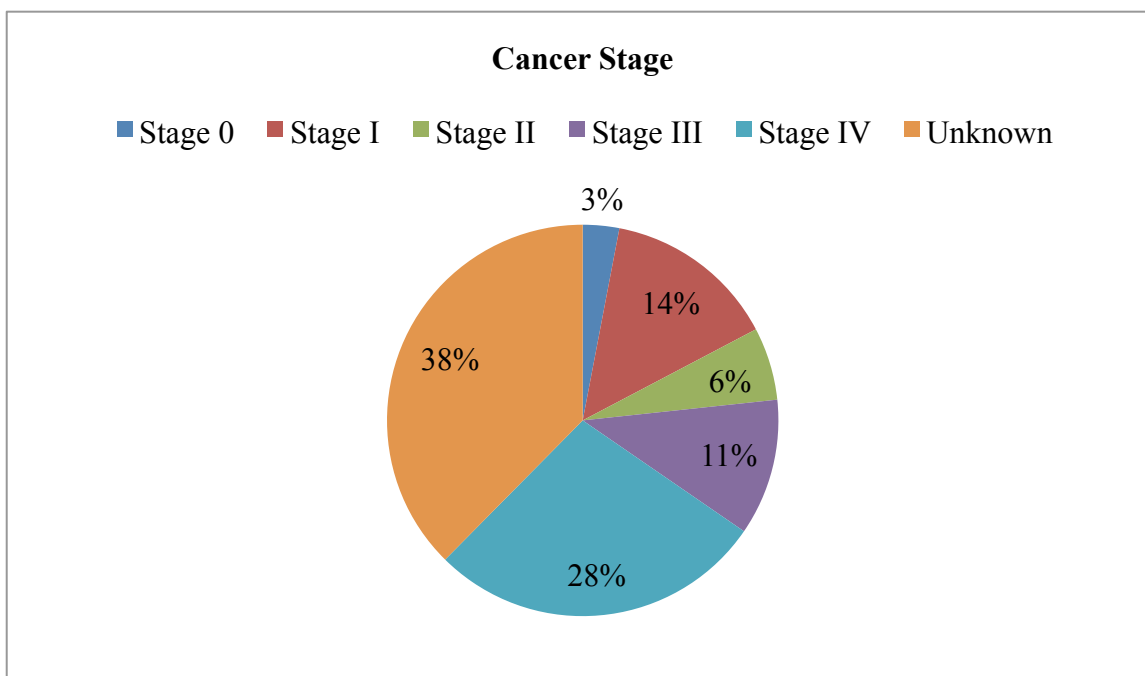


Figure 30. Patient demographics: cancer stage.

The demographics of survey respondents were compared to PRCP's population at-large. While PRCP's general population revealed predominate occurrences of patients with stage I cancer, survey respondents were much more likely to represent patients with stage IV cancer. Indeed, stage I cancer was underrepresented by survey respondents, while stage IV was overrepresented compared to PRCP's general population.

Interestingly, this trend was evident among utilization results as well, as indicated in the above sections. Among patients who participated in program services (i.e., utilization of services results) and surveys (i.e., satisfaction of services results), stage IV patients were predominately represented. This finding suggested patients with stage IV cancer were most likely to participate in program services (i.e., multiuse program participants) and most likely to respond to questionnaires about their satisfaction with program services. Patients with stage IV cancer may have been more likely to participate in the satisfaction survey based on their familiarity and use of program services, as previously indicated based on trends in utilization of services.

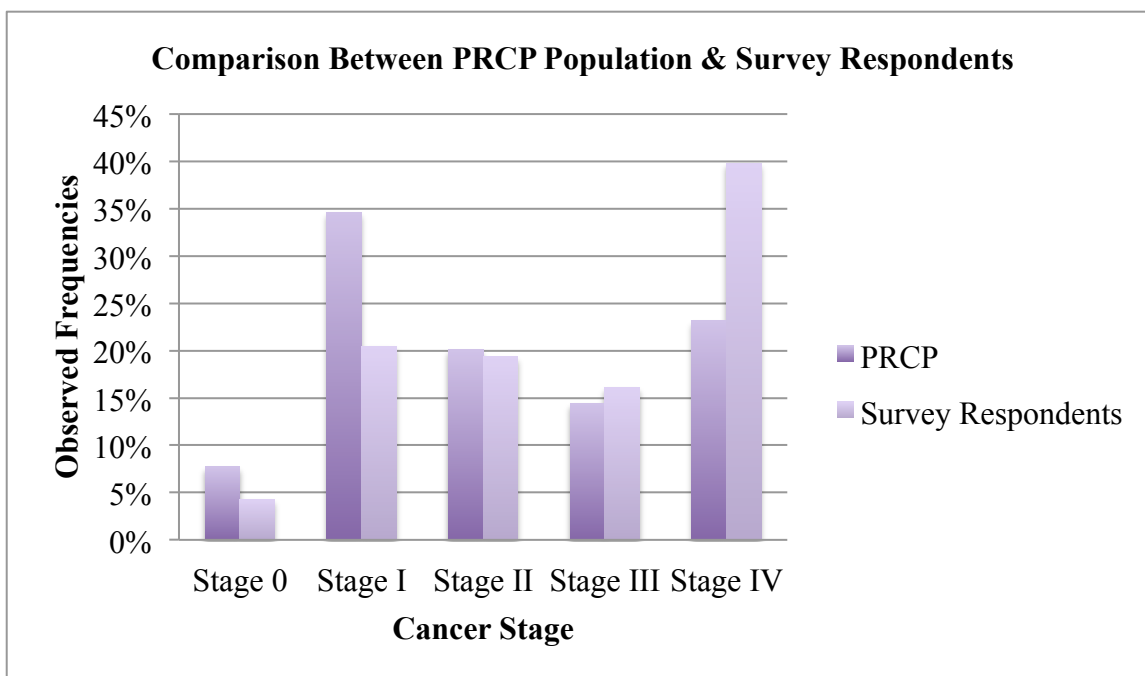


Figure 31. Comparison between PRCP population and survey respondents: cancer stage.

Respondents were well represented across the most common types of cancer treatment including biopsy ($n = 74$), surgery ($n = 62$), chemotherapy ($n = 96$), and radiation therapy ($n = 82$). Less commonly occurring treatments included hormone therapy ($n = 21$), clinical research trials ($n = 5$), palliative care ($n = 2$), and hospice care ($n = 1$). Lastly, seven respondents reported being under observation but not actively receiving treatment.

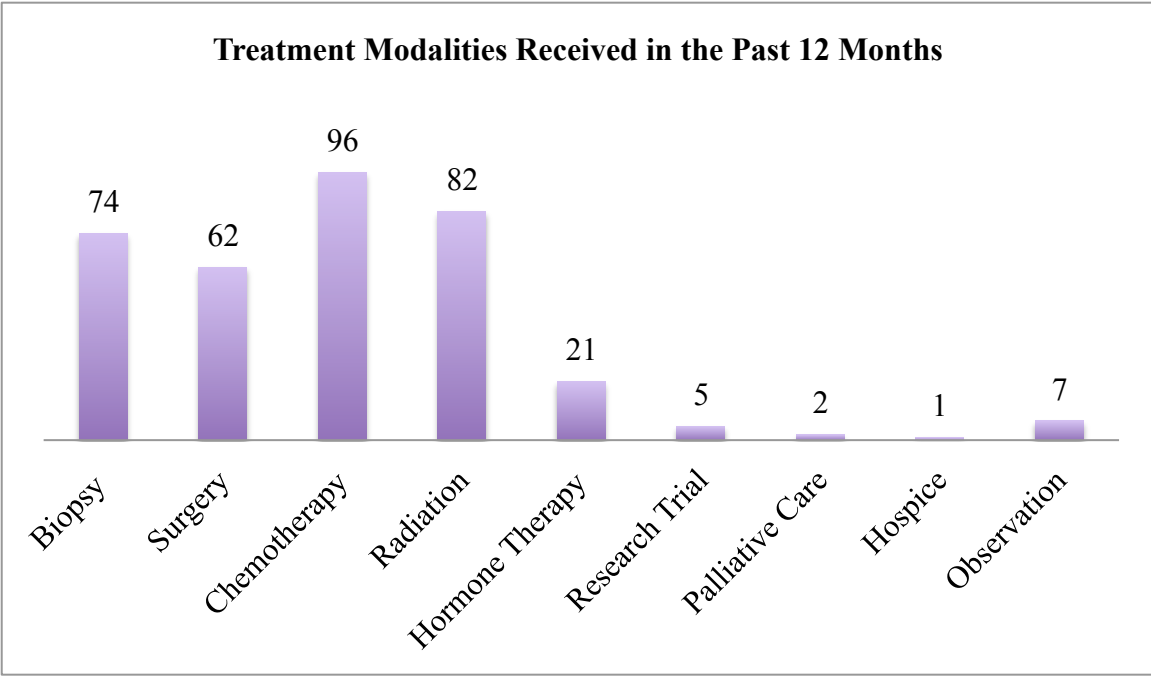


Figure 32. Treatment modalities.

Familiarity and use of program services. Forty-two percent of respondents indicated they were well informed about services available through Patient Support. An additional 40% of respondents indicated having knowledge of program services and being aware of where to go for more information as needed. Eighteen percent of respondents indicated needing more information ($n = 13$) or having no information at all ($n = 13$).

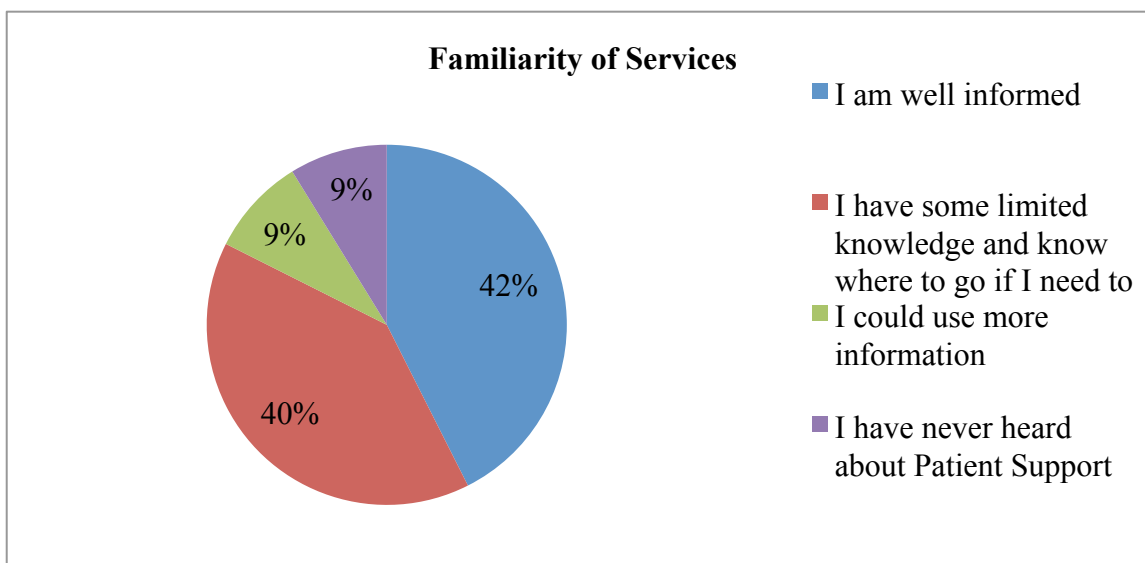


Figure 33. Familiarity of program services.

Forty-nine percent of respondents indicated using program services at one point while receiving treatment at PRCP. Of those respondents, 71 indicated which services or combination of services they used: Thirty-nine percent attended a support group, 37% utilized social work, resources, or financial assistance, 30% participated in counseling with a staff member, and 27% received emotional support from staff directly during treatment. Patients also indicated using nutrition services and attending supportive services offered through the Cancer Resource Center, including the Look Good, Feel Better class which was hosted by the American Cancer Society.

Table 16

Percentage Rates and Frequency of Patient Support Services Used

	Percentage	Frequency
Have You Used Program Services?*		
Yes	48.6%	72
No	51.4%	76
Which Services Have You Used? Select All That Apply**		
Emotional support during treatment	26.8%	19
Counseling with PSS staff	29.6%	21
Attending a support group	39.4%	28
Social work, resources, financial assistance	36.6%	26

Note. * Based on 148 responses; four blank responses. ** Based on 71 responses; 81 blank responses.

The 71 patients who reported using services during their treatment were characterized as follows: Seventy-one percent were female and 56% were between the ages 55–74. Breast cancer was the most commonly occurring cancer by far ($n = 42\%$), while the stage of cancer was nearly equally represented between stages I–IV, with stage IV cancer reported most frequently ($n = 25\%$).

Of note, the demographics of patients who reported using services on surveys were largely similar to the demographics of patients who used services according to results from the utilization of services results. Indeed, survey results appeared to corroborate the general characteristics of patients who participated in program services. Results from utilization of services and surveys suggested the most common characteristics of patients who use services were women, persons between the ages 55–75, patients with breast cancer, and stage IV cancer patients.

Table 17

Percentage Rates and Frequency of Demographics of Patients Who Used Services

	Percentage	Frequency
Gender		
Male	29.2%	21
Female	70.8%	51
Respondents Age		
26 to 34	2.9%	2
35 to 44	5.7%	4
45 to 54	21.4%	15
55 to 64	24.3%	17
65 to 74	31.4%	22
75 or older	14.3%	10
What Type of Cancer is Being Treated?		
Bladder cancer	1.4%	1
Blood cancer	16.9%	12
Bone cancer	2.8%	2
Brain tumor	4.2%	3
Breast cancer	42.3%	30
Colorectal cancer	5.6%	4
Female reproductive cancer	16.9%	12
Head and neck cancer	5.6%	4
Kidney cancer	1.4%	1
Liver cancer	1.4%	1
Lung cancer	9.9%	7
Male reproductive cancer	4.2%	3
Skin cancer	1.4%	1
Soft tissue sarcoma	2.8%	2
What Stage of Cancer is Being Treated?		
Stage 0	1.5%	1
Stage I	15.9%	11
Stage II	14.5%	10
Stage III	18.8%	13
Stage IV	24.6%	17
Unknown	24.6%	17

Satisfaction with program services. Program satisfaction results are reported separately based on patients' participation in program services during their treatment. Respondents who reported using program services are referred to as "participants" while respondents who reported

not using program services are referred to as “non-participants.” Program satisfaction was defined by respondents’ opinions and experiences regarding the quality and variety of program services as well as staffing accessibility and responsiveness.

Quality. Sixty-seven program participants responded to the survey question about satisfaction regarding the quality of program services provided by PSS staff. Results demonstrated high satisfaction with the quality of program services. Eighty-four percent of participants reported being fully satisfied, while 10% reported being somewhat satisfied. Six percent reported neutral feelings. None of the program participants reported dissatisfaction with the quality of program services provided.

Twenty-two non-participants responded to the survey question about quality of program services. Interestingly, 45% reported being fully satisfied. Fifty percent felt neutral about quality of services, while one non-participant reported full dissatisfaction.

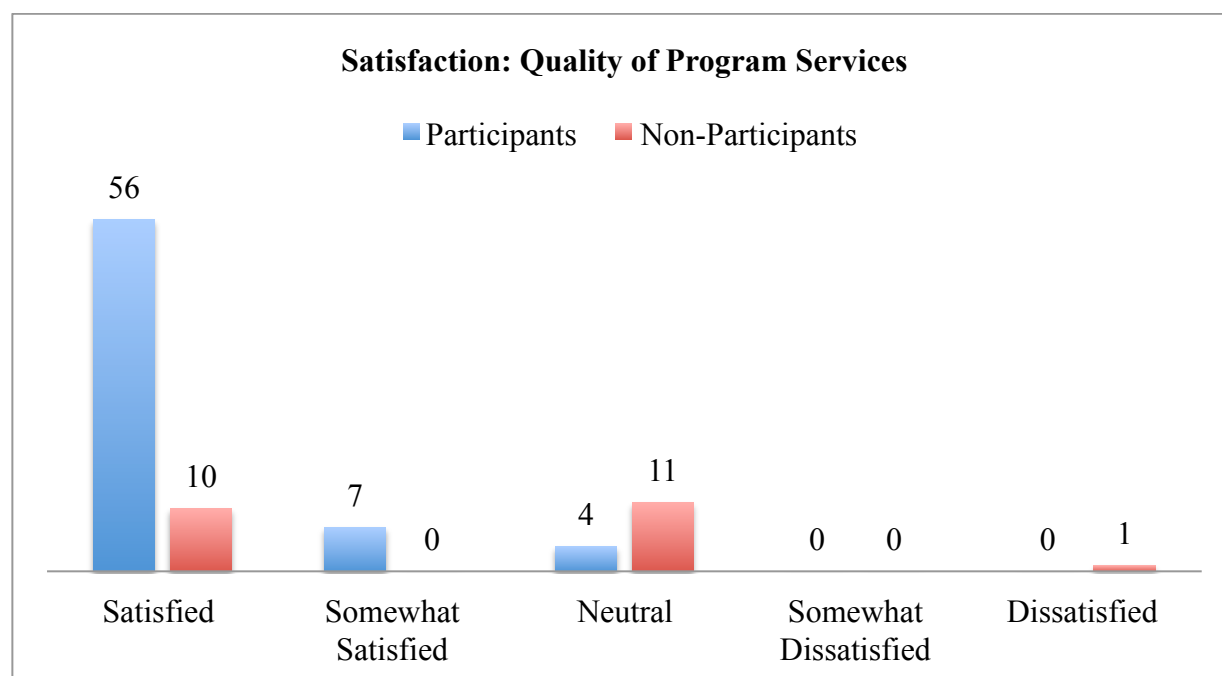


Figure 34. Patient satisfaction: quality of program services.

Variety. Sixty-eight program participants responded to the survey question about satisfaction regarding the variety of program services provided by PSS staff. Program variety also received high reviews based on participants' responses. Seventy-eight percent of program participants reported full satisfaction with the variety of programs services provided by staff. Nine percent reported being somewhat satisfied, while 12% reported feeling neutral. One participant reported being somewhat dissatisfied with the variety of program services offered.

Twenty-four non-participants responded to the survey question about variety of program services. Fifty-four percent reported being fully satisfied with the variety of program services. Forty-two percent felt neutral, while one non-participant reported full dissatisfaction.

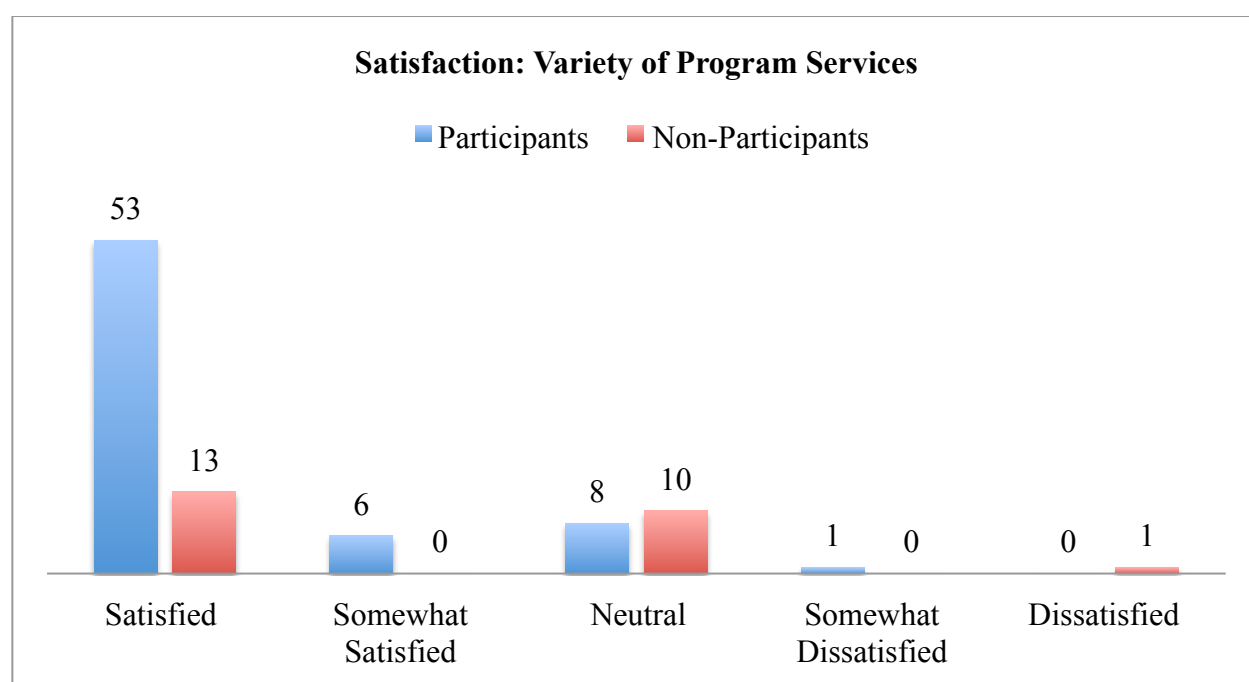


Figure 35. Patient satisfaction: variety of program services.

Staffing. Sixty-eight program participants responded to the survey question about their satisfaction with program staff. Overall, participants responded favorably regarding the accessibility and responsiveness of staff. Seventy-nine percent reported being fully satisfied.

Seven percent reported being somewhat satisfied and 13% reported neutral feelings. None of the program participants reported dissatisfaction regarding staff access and responsiveness.

Twenty-two non-participants responded to the survey question about staffing.

Consistent with non-participants views of satisfaction with program quality and variety, 45% reported being fully satisfied with staff access and responsiveness. Nine percent reported being somewhat satisfied, while forty-one percent felt neutral. One non-participant reported full dissatisfaction.

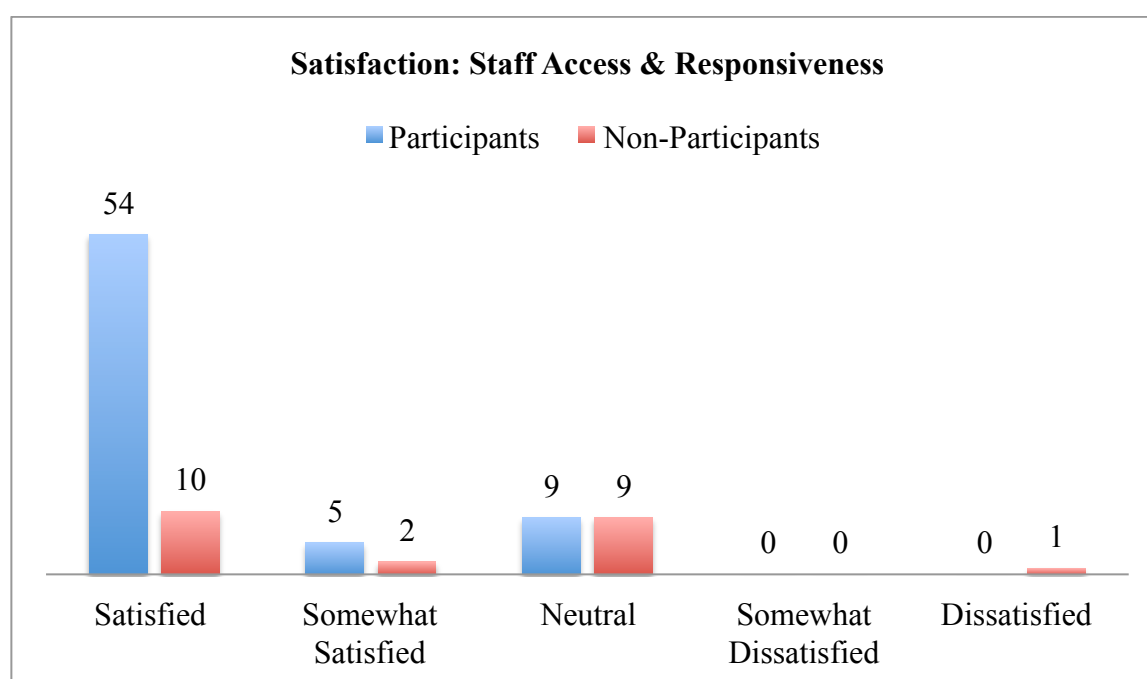


Figure 36. Patient satisfaction: staff access and responsiveness.

Overall value of program services. In general, respondents indicated they considered PSS a valuable part of their cancer treatment at PRCP. Fifty-seven percent of all respondents reported strong agreement, while 20% reported agreement. Nineteen percent of all respondents reported neutrality, of which thirteen respondents were non-participants and seven were program participants. Five percent of all respondents indicated strong disagreement regarding their

perceived value of program services; of those respondents, four were non-participants and one was a program participant.

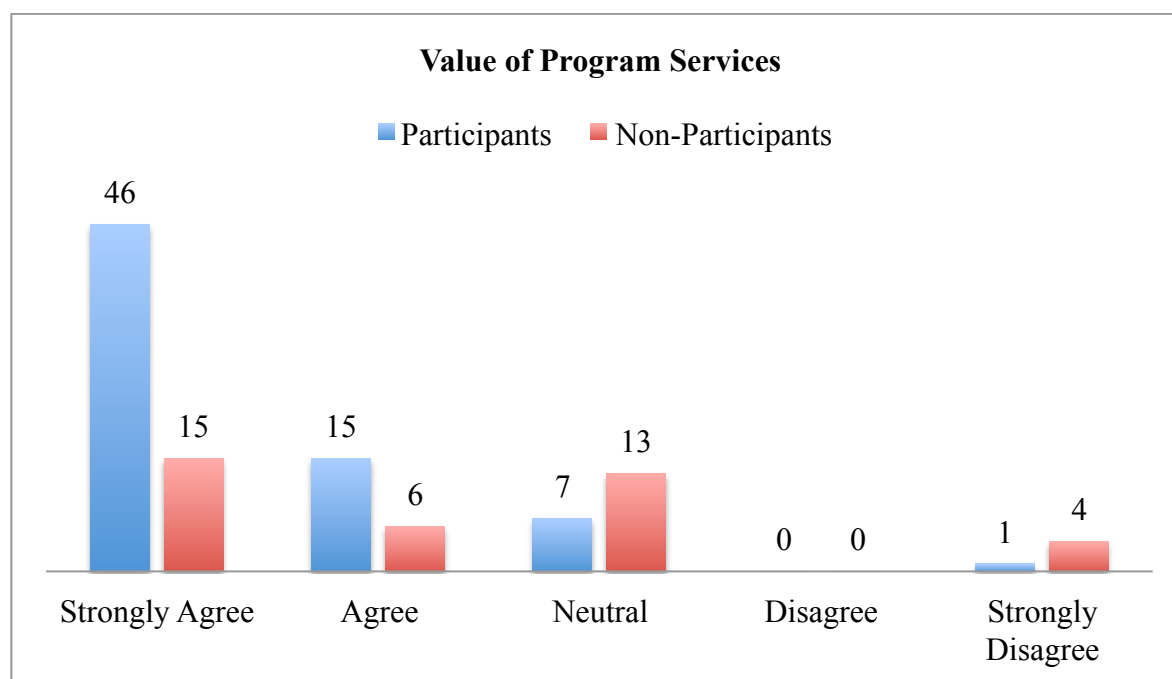


Figure 37. Patient satisfaction: value of program services.

Not surprisingly, the likelihood of respondents using program services or recommending program services to other patients and family members varied based on respondents participation in program services. Forty-one percent of all respondents reported a high likelihood of continuing to use program services or using them in the future. An additional 18% of all respondents reported being somewhat likely to participate in services, while 20% reported neutrality. Of the respondents who reported disagreement, 38% of non-participants reported being unlikely to use program services, while 9% of program participants reported being unlikely to continue using services.

Program participants were highly likely to recommend services to others ($n = 80\%$), reporting minimal ambivalence ($n = 8\%$) and no dissonance. Although non-participants

accounted for a smaller representative sample, overall they were less likely to recommend services ($n = 45\%$) and more likely to report ambivalence ($n = 10\%$) or dissonance ($n = 21\%$).

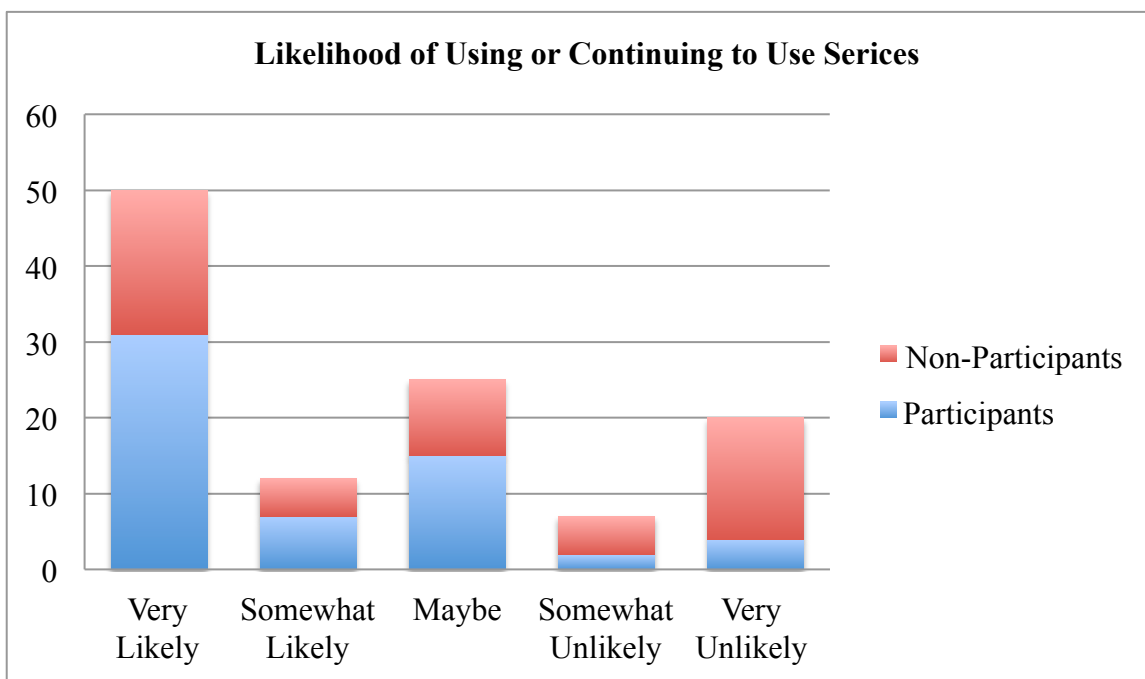


Figure 38. Patient satisfaction: likelihood of using or continuing to use program services.

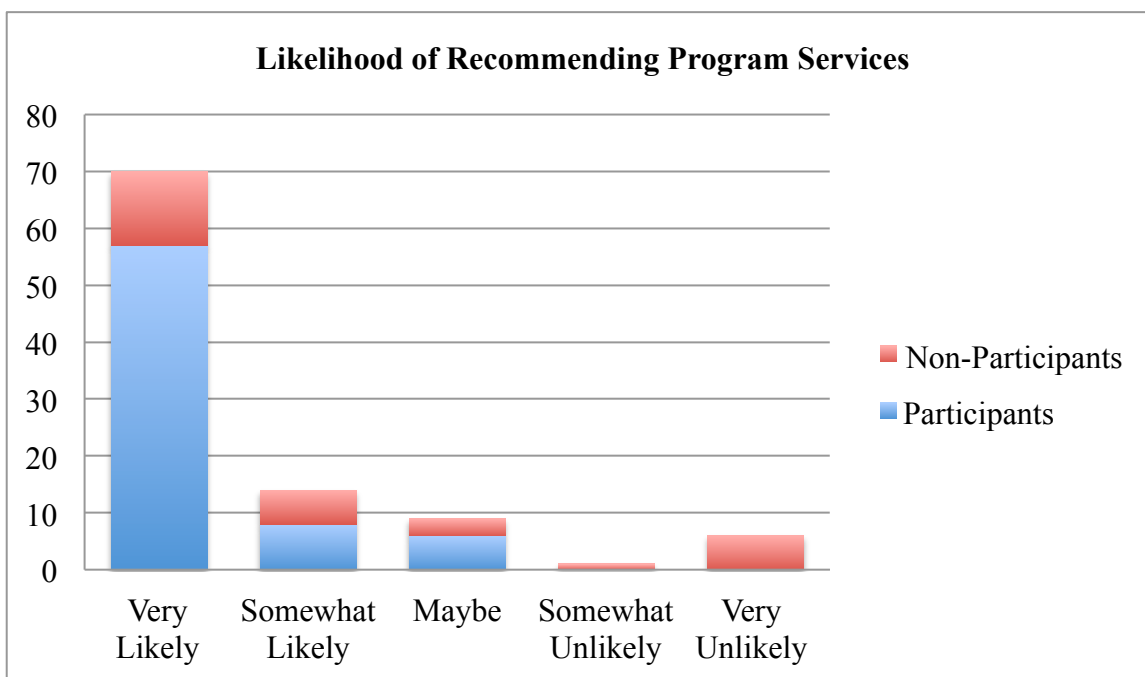


Figure 39. Patient satisfaction: likelihood of recommending program services.

Areas of strength. Areas of perceived strength are reported in aggregate form based on responses from both participants ($n = 60$) and non-participants ($n = 12$). Respondents were offered three program service choices (emotional support, support groups, resources and financial support) and asked to select the program service they viewed most helpful, though many respondents chose more than one service. Fifty percent of all respondents reported emotional support was the most helpful service provided. Support groups were viewed as most helpful by 34% of respondents, while 32% of respondents indicated access to resources and financial support was most helpful. Respondents indicated three other noteworthy support services not listed including nutrition ($n = 1$), naturopathic medicine ($n = 1$), and American Cancer Society volunteers ($n = 4$).

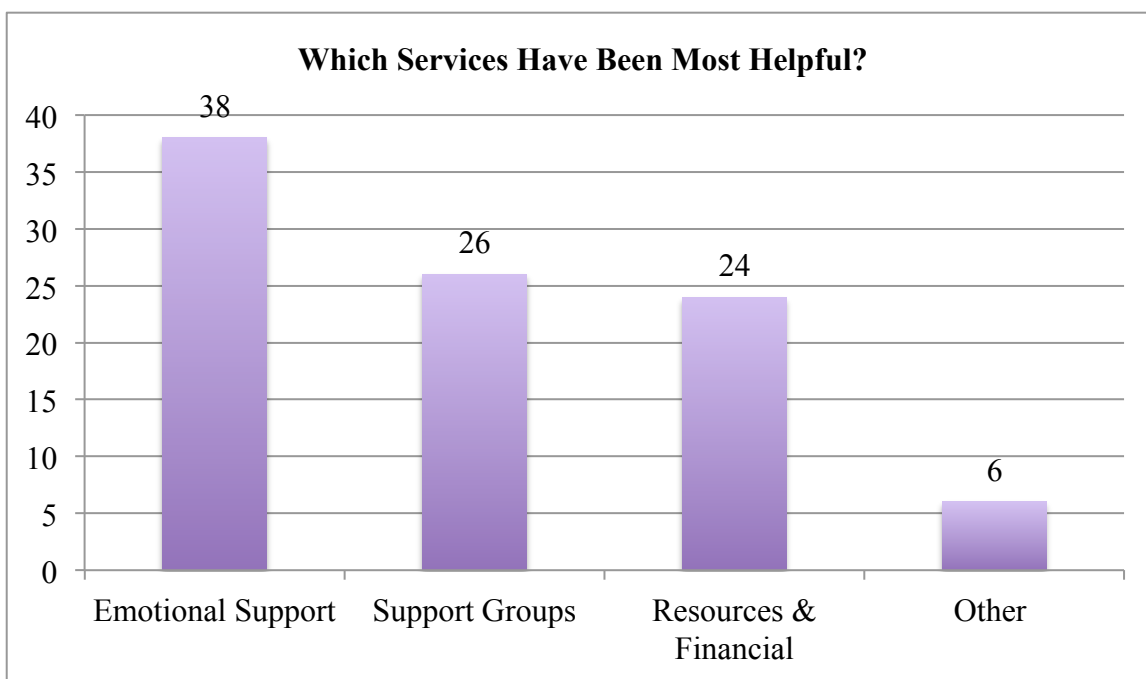


Figure 40. Patient satisfaction: areas of strength.

Areas of improvement. Respondents were asked to provide open-ended feedback about perceived areas of improvement. Thirty-eight respondents provided feedback. Interestingly, 21

respondents used this question as a platform to express gratitude or their overall satisfaction with support services. Specific critical feedback was provided by 16 respondents and categorized into three themes: (a) education and outreach, (b) services and access, and (c) PSS staffing.

Education and outreach. Several respondents recommended spending more time educating and informing patients and staff about PSS and support options. One respondent asked for greater emphasis on integrated services.

Several respondents wanted more emphasis providing patient outreach and education near the beginning of treatment. One respondent recommended holding a monthly information session for new patients and family members to learn about support service options. Another respondent requested more information advertising support group options and availability or meeting times. A third respondent wanted medical providers to offer “stronger encouragement” to patients to use support services.

Services and access. Respondents recommended several areas of interest related to available support service options. Areas of improvement included transportation services, transitioning to hospice care, and family and caregiver support opportunities. One respondent asked for more support services specifically for breast cancer. In addition, a request was made to offer support group options more frequently (i.e., weekly) as well as making weekend support available for patients.

PSS staffing. Staffing concerns were less likely to be identified as an area of improvement; however, two respondents indicated frustration with the lack of training/education or consistency among support staff persons. Another respondent expressed disappointment with the department not being “sufficient,” though more specific information was not provided.

Staff satisfaction. In total, 110 staff were invited to participate in a survey including: medical and radiation oncologists ($n = 11$), advanced care practitioners ($n = 4$), nurses ($n = 31$), medical assistants ($n = 11$), other clinical staff ($n = 16$), nonclinical support staff ($n = 15$), and administrators ($n = 22$). Other clinical staff included clinical nurse specialist, palliative care, nutrition, pharmacy, phlebotomy, and radiation therapy technology. Nonclinical support staff included financial counseling, patient navigation, clinical research, radiation physics, medical dosimetry, nuclear medication technology and information technology. The administration team consisted of receptionists, schedulers, health information services, administration assistants, and administration management. Forty-one staff completed the survey, accounting for a higher than average return rate of 37%.

Staff demographics. Of the 41 surveys returned, the nursing team provided the most responses with 42% of nursing staff participating. Four physicians and two medical assistants responded accounting for 15% of the total responses; however, physicians and medical assistants represented a fairly low response rate given the size of their departments (36% and 18% response rate, respectively). Advanced care practitioners did not participate in the survey, which may be related to concerns regarding anonymity given their small numbers among all staff ($n = 4$). Conversely, a high percentage of support persons participated representing 73% support staff persons, 31% clinical staff persons, and 22% of administrative staff persons.

Table 18

Staff Demographics: Employment Position

Employment Position	Invited	Responded	Response Rate
Physician	11	4	36.4%
Advanced Care Practitioner	4	0	0%
Nurse	31	13	41.9%
Medical Assistant	11	2	18.2%
Other Clinical Staff	16	5	31.3%
Support Staff	15	11	73.3%
Administration	22	5	22.7%
Anonymous	n/a	1	n/a
Total	110	41	

Staff who responded to the survey most frequently were also those staff members employed at PRCP the longest, serving 7–8 years ($n = 18$). Staff members least likely to respond were those employed less than one year ($n = 3$) as well as those employed 3–4 years ($n = 3$).

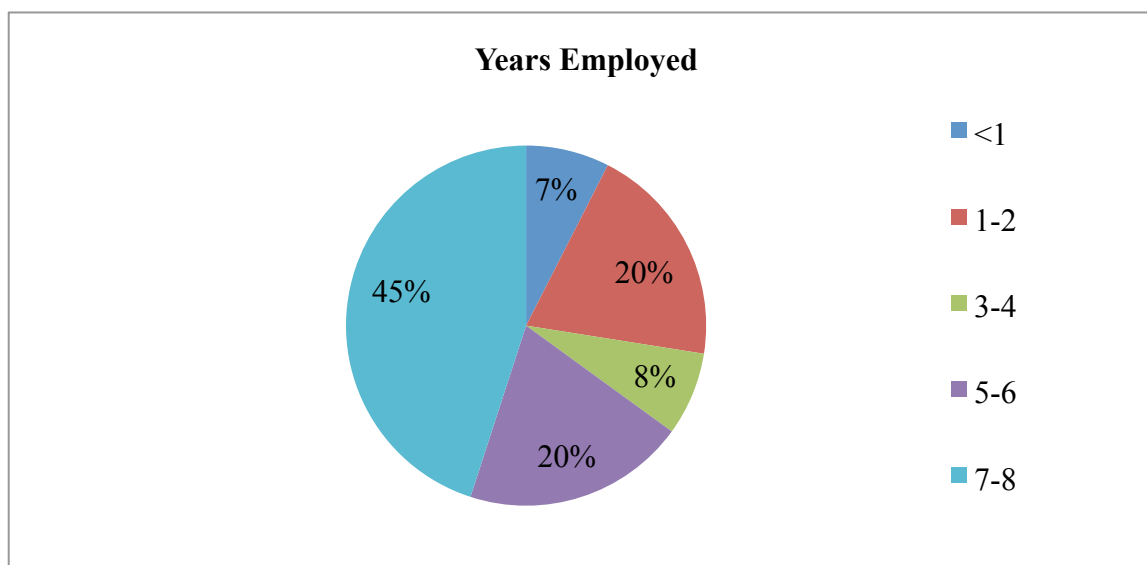


Figure 41. Staff demographics: number of years employed at PRCP.

Familiarity with program services. Sixty-eight percent of respondents indicated they were familiar or very familiar with services offered by PSS. Two percent indicated they were not familiar with PSS at all, while 29% reported some familiarity.

Table 19

Percentage Rates and Frequency of Patient Support Services Familiarity

	Percentage	Frequency
How Familiar Are You With Services Offered?		
(1) Very familiar	43.9%	18
(4) Familiar	24.4%	10
(3) Somewhat familiar	24.4%	10
(2) A little familiar	4.9%	2
(1) Not at all	2.4%	1

Note. Based on a Likert-scale, where 5 is very familiar with services and 1 is not at all familiar with services.

Referrals to program services. Despite a high percentage of respondents indicating their familiarity with PSS, fewer than half the respondents reported frequent referrals. Thirty-six percent of respondents reported referring to PSS often to very often. Ten percent of respondents indicated they did not refer to PSS at all, while 45% of respondents reported sometimes referring to PSS. It is worth noting, these findings did not account for staff positions and whether low referrals represented staff with minimal patient interaction or clinical providers. It is likely that low referrals were, in part, attributed to nonclinical staff positions rather than poor familiarity with program services, since PRCP indicated good familiarity with PSS in the above survey question.

Table 20

Percentage Rates and Frequency of Patient Support Services Referrals

	Percentage	Frequency
How Often Do You Refer to PSS?		
(1) Very often	24.4%	10
(4) Often	12.2%	5
(3) Sometimes	39.0%	16
(2) Not very often	14.6%	6
(1) Not at all	9.8%	4

Note. Based on a Likert-scale, where 5 is very familiar with services and 1 is not at all familiar with services.

PSS resources most frequently recommended to patients were social work (66%) and counseling (61%). The Cancer Resource Center (59%), support groups (56%), nutrition (54%), and financial resources (51%) were also highly recommended by staff. One respondent reported referring patients for cognitive testing while another respondent commented “other,” reporting transportation concerns as a referral reason. Six respondents noted they did not recommend PSS to patients given their employment position.

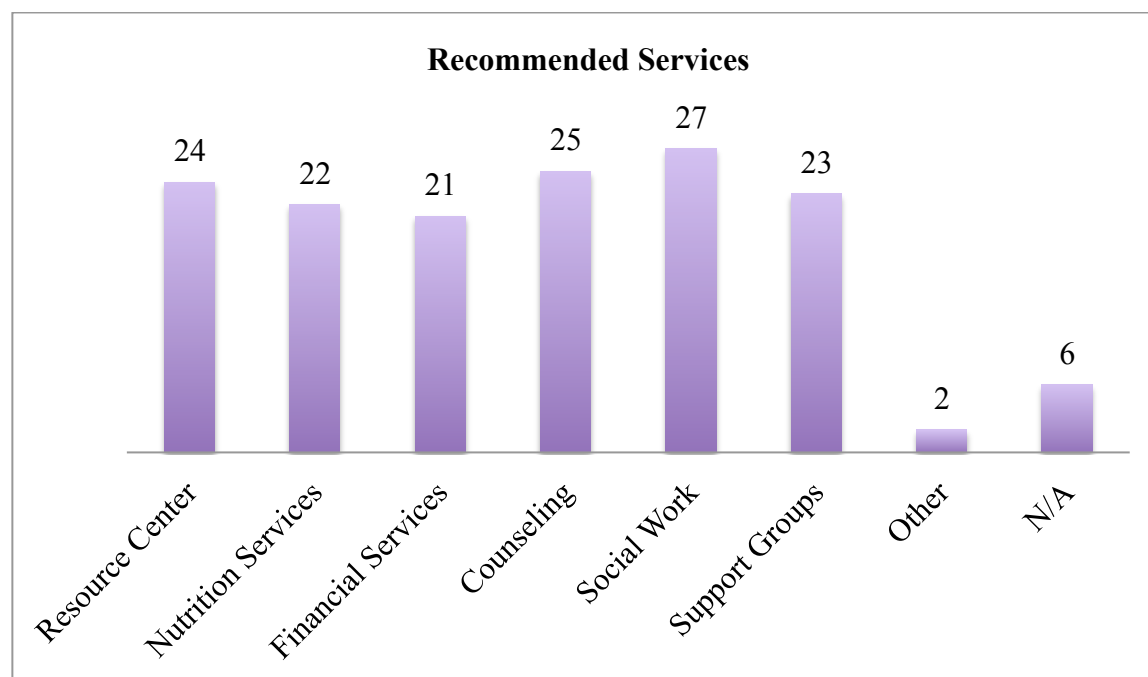


Figure 42. Staff satisfaction: recommended Patient Support Service resources.

When asked about the circumstances or situations staff members typically referred patients to PSS, respondents identified four scenarios most frequently: patients expressing emotional distress ($n = 70\%$), concern or support for family members ($n = 66\%$), complex medical and/or psychosocial concerns ($n = 63\%$), and transportation concerns ($n = 63\%$). Three additional scenarios were identified with great frequency: concerns regarding risk of self-harm or injury ($n = 59\%$), financial stress ($n = 54\%$), and nutrition concerns ($n = 51\%$). Thirty-seven percent of respondents said they referred patients to services when upsetting news was received or delivered, while only 15% of respondents reported referring patients whose health has declined. Twenty-seven percent of respondents reported referring to services when a patient upset staff or other patients. Twenty-two percent of respondents reported referrals when concerns about patients' cognitive skills or comprehension were questioned, while only 15% of respondents made referrals when patients had difficulty understanding their disease and treatment options.

Several respondents also reported unique circumstances that preceded their referral to PSS including, palliative care services ($n = 1$), high levels of distress indicated on PRCP's Distress Assessment form ($n = 1$), or when staff encountered a patient complaint or concern ($n = 1$). Fourteen percent of respondents ($n = 6$) indicated they did not refer patients to services given their employment position.

Table 21

Percentage Rates and Frequency of Referral Scenarios

	Percentage	Frequency
What Types of Situations Do You Typically Refer Patients to PSS? Select All That Apply:		
When a patient appears upset or distraught	70.7%	29
When a patient receives upsetting news	36.6%	15
When family has concerns or needs support	65.9%	27
When a patient has difficulty understanding diagnosis, prognosis, or treatment options	14.6%	6
When a patient appears cognitively impairment or has difficulty comprehending	22.0%	9
When a patient's health begins to decline	14.6%	6
When a patient has complex medical or psychosocial needs	63.4%	26
When a patient appears at risk of self-harm or injury	58.5%	24
When a patient has upset staff or other patients	26.8%	11
When a patient has financial concerns	53.7%	22
When a patient has transportation concerns	63.4%	26
When a patient would benefit from a nutrition consultation	51.2%	21
What a patient would benefit from additional time or attention	41.5%	17
Not applicable: I do not refer patients in my position	14.6%	6
Other	7.3%	3

Overall value of program services. Eight-five percent of respondents indicated they very much considered Patient Support Services a valuable part of PRCP's cancer treatment program. Ten percent of respondents stated that PSS services were moderately valuable, while two respondents responded that services were only somewhat valuable. No respondents indicated a lack of value regarding PSS.

Similarly, the majority of respondents stated PSS had a positive to very positive effect on treatment outcomes for patients ($n = 35$). Twelve percent of respondents stated that services had a somewhat positive effect on outcomes, while one respondent disagreed indicating that PSS had little positive effect on outcomes.

Table 22

Percentage Rates and Frequency of Patient Support Services Value

	Percentage	Frequency
Do You Consider PSS a Valuable Part of PRCP?*		
(1) Very much	85.0%	34
(4) Moderately	10.0%	4
(3) Somewhat	5.0%	2
(2) A little	0%	0
(1) Not really	0%	0
Does PSS Positively Affect Treatment Outcomes?		
(1) Very much	63.4%	26
(4) Moderately	22.0%	9
(3) Somewhat	12.2%	5
(2) A little	2.4%	1
(1) Not really	0%	0

Note. Based on a Likert-scale, where 5 is very familiar with services and 1 is not at all familiar with services. * Based on 40 responses; one blank response.

Staff members were also asked to endorse the perceived benefits of including psychosocial services as an integrative program within cancer treatment. Respondents were most likely to agree that psychosocial services helped improve patients' ability to cope with expected distress associated with cancer treatment ($n = 90\%$) and reduced the risk of developing more severe emotional disorders ($n = 88\%$). A high percentage of respondents also agreed that psychosocial services helped improve the satisfaction of services available for cancer treatment ($n = 83\%$) and improved patient compliance with treatment and follow up care ($n = 80\%$). Sixty-five percent of respondents agreed that psychosocial services helped improve patients' overall health and functioning. Respondents were less likely to agree that psychosocial services helped reduce the financial costs of the medical system ($n = 50\%$), the use of unnecessary medical services ($n = 55\%$), or the workload for treatment providers or staff ($n = 48\%$).

Table 23

Percentage Rates and Frequency of Patient Support Services Perceived Benefits

	Percentage	Frequency
What Outcomes May Be Likely Because of Patient Involvement in PSS? Select All That Apply:		
Reduced risk of severe emotional disorders	87.5%	35
Improved ability to cope with expected distress	90.0%	36
Improved overall health and functioning	65.0%	26
Improved satisfaction with cancer care services	82.5%	33
Increased treatment compliance and follow up	80.0%	32
Reduced workload for providers and staff	47.5%	19
Lower use of unnecessary medical services	55.0%	22
Reduced financial costs to our medical system	50.0%	20

Note. Based on 40 responses; one blank response.

Areas of strength. Eight-five percent of respondents were in agreement that the greatest strength of PSS was the team's ability to provide emotional support to patients and family members. According to respondents, the team's second greatest strength was its ability to provide crisis intervention and risk assessment ($n = 66\%$). The third area of strength identified was PSS's ability to assess psychosocial needs ($n = 63\%$). Triageing patients with high acuity and facilitating support groups were less frequently reported as department strengths ($n = 56\%$). Two respondents replied "other" and identified the program's strengths as providing financial assistance and transportation. Two additional respondents stated they were unfamiliar with program strengths given their employment position.

Table 24

Percentage Rates and Frequency of Patient Support Services Strengths

	Percentage	Frequency
What Does the PSS Team Do Particularly Well?		
Select All That Apply:		
Assess psychosocial needs	63.4%	26
Facilitate support groups	56.1%	23
Provide emotional support to patients and family	85.4%	35
Provide crisis intervention and risk assessment	65.9%	27
Triage patients with high acuity or distress	56.1%	23
Other	9.8%	4

Areas of improvement. Respondents identified several areas for program improvement with high consistency. The two greatest areas of concern identified by respondents were accessibility of staff ($n = 27$) and responsiveness to urgent needs ($n = 21$). Respondents commented about the importance of staff responding to urgent concerns more readily and being available for personal referrals from staff. Of mention, respondents noted difficulty reaching staff by phone during regular business hours and one respondent requested faster response time following up with patients who report high levels of distress on Distress Assessment questionnaires. One respondent also suggested increasing staff access on Fridays. Two respondents recommended staff walk around the infusion center to make themselves more available to patients; additionally, two respondents wanted to ensure all patients were being followed by PSS staff and mentioned the importance of having an initial meeting with PSS staff as part of treatment orientation. Three respondents made requests for additional staff, including first floor reception staff to help with patient check-in for psychosocial services and more full-time employees in PSS including a full-time nutritionist/dietician and full-time social worker.

The third most frequently identified area of concern was the diversity of support service options ($n = 12$). Two respondents made specific requests for more options being made available for caregivers or family members of patients.

Increasing publicity or marketing to recruit patients was identified with similar frequency ($n = 11$). One respondent recommended business cards being made more readily available for distribution, while another respondent requested better staff education regarding program services, making referrals, and how to contact staff.

Respondents were least likely to identify revenue or funding opportunities as an area in need of improvement ($n = 5$) or modifying the frequency of support group meetings ($n = 7$). Three respondents did not recommend any areas for improvement while six respondents stated they were unsure of areas in need of improvement.

Table 25

Percentage Rates and Frequency of Areas for Program Improvement

	Percentage	Frequency
What Can PSS Do To Improve Its Services? Select All That Apply:		
Increase staff access during business hours	65.9%	27
Improve staff response time for urgent needs	51.2%	21
Offer support groups more frequently	17.1%	7
Offer more support service options	29.3%	12
Generate revenue or funding opportunities	12.2%	5
Improve publicity or marketing to recruit patients from the community	26.8%	11
Nothing! Keep doing what you are doing!	7.3%	3
I'm not sure	14.6%	6
Other	17.1%	7

Chapter IV: Discussion

This evaluation examined Patient Support Services to determine what aspects of the program were working well and what areas needed improvement. Evaluation findings provided an overview of program services as they were currently utilized and valued by patients and staff. The culmination of this evaluation presented stakeholders with informed recommendations to improve program services based on identified areas of satisfaction and dissatisfaction. Evaluation findings were presented to stakeholders on multiple occasions to collaboratively discuss program strengths and areas for improvement. Recommendations were generated with input from PSS staff and offered to stakeholders and program administrators to make informed decisions about desired future program changes. An executive report was provided outlining evaluation findings and recommendations for consideration (see Appendix R).

The following sections provide an overview of program strengths, areas identified for improvement, program recommendations, and limitations of this evaluation.

Program Strengths

Many areas of strength were identified during the program evaluation. Indeed, the value and worth of Patient Support Services was clearly demonstrated from the perspective of program utilization as well as program satisfaction. Program strengths provide insight into services that were well utilized and most valued; areas of strength should continue to receive attention from PSS staff as program recommendations are considered.

Utilization of services. An analysis of program services was conducted to better understand how program services were utilized and by whom, identifying program services that were well utilized or well represented by patients. In general, an analysis of utilization of services demonstrated alignment with the overall mission of PSS: To reach a broad patient

population and provide services to some of PRCP's patients in greatest need. Three areas of strength were identified:

- While this evaluation was not an exhaustive analysis of services utilized by all patients but a snapshot of services provided during a specific timeframe, it did demonstrate that more than 17% of all new patients at PRCP participated in program services beyond Distress Assessments. While all patients are assessed for low, moderate, and high levels of distress based on NCCN (2016b) guidelines, 330 of 1,904 all new patients participated in at least one program service beyond Distress Assessment. Further, 83% of patients who utilized program services ($n = 330$ of 400) interacted with PSS beyond Distress Assessment. These findings suggest that PSS reaches an expansive population of patients beyond screening requirements as outlined by NCCN.
- Participation in program services appeared to be reflective of patients' needs and presumed financial resources according to primary payer information. In general, patients presumed to have the fewest financial resources participated in program services more frequently and diversely, compared to patients presumed to have better access to financial resources and support opportunities. Medicaid patients were more likely to participate in nearly all program services, despite comprising only 16% of program participants and 7.5% of all new cancer cases. Medicare patients represented the largest portion of all patients (52.6%) and were most likely to request follow up on Distress Assessment questionnaires, likely because Medicare patients represent an older patient population or medically disabled persons with complex needs and, therefore, requests for follow up on psychosocial

questionnaires can be expected. Alternately, patients with commercial insurance presumably represent younger or actively employed persons with greater access to financial resources and support. Patients with commercial insurance were twice as likely to participate in support groups, taking advantage of peer support opportunities more so than other program resources suggesting a greater interest in building a supportive, peer community.

- Patients with advanced stage cancer were shown to use program services more frequently and diversely. While patients with Stage IV cancer represented 19.7% of all new cancer cases at PRCP, they represented 53% of multiuse participants. Assuming patients with advanced stage cancer face greater emotional distress and more complex psychosocial needs than patients with earlier stage cancer, advanced cancer patients' vast participation in program services affirms the mission of PSS to meet the needs of patients in distress.

Patient perspective. Patient surveys sought to elicit areas of program strength based on patients' understanding of services or experience participating in services. Patient feedback revealed many encouraging areas of program services and, in general, patients were likely to express satisfaction and gratitude for the program. What follows is a summary of areas of patient satisfaction based on 152 returned surveys.

- Eighty-two percent of patients reported being informed of program services.
- Emotional support was identified as the program's greatest strength and most helpful service provided by staff, with support groups being ranked second and resources and financial support ranked third.

- The vast majority of patients reported high satisfaction with the quality (82.6%) and variety (77.6%) of program services currently offered.
- Eighty percent of patients reported satisfaction with staff access and responsiveness
- Psychosocial services were perceived as a valuable part of cancer care treatment by 76.3% of patients.
- Patients who had used program services were highly likely to continue using services and to refer others to program services.

Staff perspective. Staff surveys aimed to understand how program services were used by staff, what services were considered most valuable, and if the inclusion of psychosocial services had an affect on staff as well as the larger cancer treatment program at PRCP. Forty-one staff completed the survey identifying the strengths and value of program services from staff perspective.

- Sixty-eight percent of staff reported familiarity with program services.
- The majority of staff regarded psychosocial services as being a valuable part of cancer care treatment (92.7%) and having positive effects on patient outcomes (85.4%).
- Similar to patient feedback, staff also identified emotional support as the program's greatest strength.
- All program services were recommended with high consistency among staff. Social work was the most referred resource followed by counseling.
- Staff reported being most likely to refer patients to program services under three circumstances which support the goals and mission of PSS: When patient is upset,

- when family members have concerns or need support, and when a patient presents with complex medical or psychosocial needs.
- Staff were in high agreement of the perceived benefits of PSS. When psychosocial services are offered in tandem with medical procedures to treat cancer, staff were likely to endorse the beliefs that (a) patients are better able to cope with emotional distress, (b) patients are less likely to develop severe emotional disorders, and (c) patients are more likely to be satisfied with their cancer care. Additionally, staff thought participation in program services was likely to increase compliance with treatment recommendations and improve patients' overall health and functioning.

Program Limitations and Recommendations

Program limitations were identified based on underutilized or underrepresented program services as well as areas of dissatisfaction reported by patients and staff. Program recommendations are offered with input from stakeholders to further benefit program services based on identified areas of concern. In general, program recommendations may assist stakeholders and staff delivering services in staying accountable to the program goals, mission, and values, understanding program issues, examining areas of concern, refining program planning, and making program decisions (Fitzpatrick et al., 2004).

In many instances, proposed recommendations affect more than one area of improvement. For example, making improvements to staff and patient education, enhancing outreach efforts, and modifying marketing materials may each have an aggregate affect on program utilization and satisfaction of services. The proposed recommendations are offered as considerations, not as prescriptive or required program changes.

Utilization of services. While program strengths were identified based on areas well utilized and well represented by patients, trends in program services that were underutilized or underrepresented by patients were identified as areas in need of improvement. Feedback is offered to diversify program services and reach patients who appear to be underserved by PSS currently. Contextualized recommendations are proposed to improve services available as well as program marketing and recruiting.

Diversity of services (gender). Although new cancer cases were represented by men and women nearly equally at PRCP, PSS saw a significantly higher portion of women (68%) than men (32%) participate in program services. Indeed, men represented less than a third of program participants despite comprising 44% of all new cancer cases at PRCP. Of those men who participated in program services, 15% represented group users and 36% represented multiuse participants. In general, it appeared that men were much less likely than women to seek services beyond an initial screening with PSS staff. It should be noted, however, that men diagnosed with prostate cancer represent 5.5% of all new cancer cases at PRCP, but may never access PSS because their treatment may be limited to surgical oncology or surveillance only, rather than ongoing oncology care typical of other cancer diagnoses. Regardless, women demonstrated much higher rates of utilization than expected compared to general demographics of PRCP patients.

Proposed recommendations. Given the low frequency of men among program services despite being near equally represented among new cancer cases, PSS is encouraged to modify current marketing materials to recruit men with cancer more explicitly and encourage their participation in program services. Further exploration is also recommended to better understand

what program services men may be most interested in receiving as current program services may not accurately reflect the needs of men with cancer.

Diversity of services (cancer). Breast cancer patients were superiorly represented among all other program participants and, consequently, across all program services. While national prevalence rates estimate that breast cancer comprises 14.6% of all new cancer cases (NCI, 2016), patients with breast cancer represented 19.4% of all new cases at PRCP and 34.8% of all program participants in this evaluation. Breast cancer patients were represented at much higher rates than expected, nearly one and half times the frequency of all other single and multiuse participants and nearly ten times the frequency of all other group participants. Participation rates of patients with other cancer diagnoses paled in comparison to the frequency of breast cancer patients, despite similarly high national prevalence rates.

Proposed recommendations. The NCI (2016) projects breast, lung, prostate, colorectal, bladder, melanoma, renal, leukemia and lymphoma, endometrial, and pancreatic cancers to be the most common cancers among new cases diagnosed in 2016. PSS should make a concerted effort to market program services to be inclusive and representative of the most commonly occurring cancer diagnoses. Considerations should be made during program planning to recruit a more diverse group of patients that parallels national prevalence rates and PRCP demographics. A follow up analysis may evaluate why frequently observed cancer diagnoses are underrepresented among PRCP cases and/or program participants. For example, male reproductive cancers represent high national prevalence rates comparable to breast cancer (11.2%), and yet represent only 6.5% of all new cases at PRCP and, as such, are significantly underrepresented among program users as well.

Support groups. Data from utilization of services indicated several considerations regarding how support groups are currently structured and valued. Despite the ability of support groups to capture a large and diverse audience, current support groups appear to be dominated by a fairly homogeneous group, namely patients with early stage cancer and women with breast cancer. In general, support groups were utilized less frequently than office visits and ranked lower than emotional support and counseling services by patients and staff alike. Indeed, evidence of the underutilization of support has been present as far back as 2005, when psychosocial services were offered as ambulatory services prior to PRCP being built (PRCP, 2005b). Anecdotally, past and present PSS staff reported low weekly attendance among support groups with few new patients returning beyond an initial support group meeting. Although support groups have received mixed feedback from patients and staff, they have the potential to provide substantial support to a large audience and deserve more attention to ensure their usefulness.

Proposed recommendations. Given the mixed feedback support groups received from patients and staff alike, it is worth evaluating how support groups are currently utilized, including the diversity of attendees and the ratio between new and returning attendees. Utilization data indicated that support groups are currently dominated by a fairly homogenous patient population; because of the advantages support groups have in reaching a broad community, attention should be paid to how support groups can recruit a more diverse audience that encompasses commonly occurring cancers at PRCP.

PSS is encouraged to consider how support groups are currently structured to evaluate how many support groups may be necessary to meet the emotional needs of patients, caregivers, and family members. Future program planning may investigate whether current support groups

should be consolidated to reach a higher volume of patients rather than a specialized population, for example support groups for all men or all women with cancer rather than focusing on prostate or breast cancers. Additionally, the structure of support groups should be evaluated to consider the benefit of offering open verses closed groups requiring preregistration or groups held for a specified length of time rather than ongoing. An appraisal of support groups may also consider what areas of interest tend to attract a higher volume of attendees to improve support group content and recruiting efforts. For example, in the past, guest speakers have attracted a high volume of attendees and it may be worth allocating funds toward speakers to increase the overall value of support groups.

Satisfaction of services. Using surveys, patients and PRCP staff were invited to submit feedback and ideas to improve PSS services. In total, 48 responses were received, 16 from patients and 32 from staff members. Responses were organized based on shared themes and categorized into three identified areas for improvement: (a) education and outreach, (b) services and access, and (c) PSS staffing.

Education and outreach. Results from patient and staff surveys indicated education and outreach as an area in need of improvement. Patients requested staff members place greater emphasis on utilizing “integrative services,” or services available beyond standard medical treatments. PRCP offers several ancillary support services under the umbrella of integrative health, including acupuncture provided by practitioners of Bastyr University, naturopathic medicine, nutrition classes with a registered dietician, and behavioral health and counseling services provided by PSS. In addition, the Cancer Resource Center, staffed by the knowledgeable Patient Navigator and volunteers from the American Cancer Society, offers a plethora of literature on cancer and treatments as well as resources such as hats, wigs, port pillows, and

camisoles to support breast prostheses. Palliative Care clinicians help manage treatment-related symptoms and pain control, focusing on preserving patients' quality of living and chaplains employed through Providence Medical Center are available for spiritual care and emotional support. For the purpose of this evaluation, data was collected primarily on behavioral health and departments that worked most closely with PSS including nutrition and the Cancer Resource Center; acupuncture, naturopathic medicine, Palliative Care, and Spiritual Care were not explicitly evaluated.

Staff education. According to staff surveys, only 37% of PRCP staff made referrals to PSS “often” and 39% of staff referred “sometimes.” While the vast majority of staff (92.7%) agreed that psychosocial services are a valuable part of cancer care treatment, 32% of staff reported being unfamiliar with PSS. Furthermore, patients felt their treatment providers did not actively encourage PSS services as part of their treatment. Better staff education is necessary to help PSS to retain its importance and value within the cancer treatment center. After all, a robust integrative health department is only as valuable as the use it receives from patients. Staff education and encouragement to use supportive services can breathe new life into ancillary services and provide the recognition integrative health deserves.

PSS staff is encouraged to create a quarterly newsletter to advertise program services and introduce PSS staff members and areas of specialty or interest. Because a majority of PSS is comprised of psychology interns, the department sees a fair deal of staff turnover annually; in essence, the department changes with each new cohort of interns and PRCP at large needs a better way to acclimate to program and staffing changes. Newsletters are a great way to familiarize PRCP with the most accurate department information, including program services,

referral information, and current staff members. It would follow that greater familiarity with PSS staff and program services would generate more frequent referrals from treatment providers.

The more visible PSS staff are throughout the cancer program, the more familiar PRCP staff will be with staff members, program services, and procedural policies. As such, PSS is encouraged to have a department representative attend quarterly all staff service meetings and daily cancer specialty conferences. Greater involvement from PSS staff within the Cancer Partnership reinforces the mission of PRCP to provide comprehensive cancer care. To that effect, PSS should be represented among the other disciplines as often as possible. Similarly, PRCP staff should also be more involved in understanding PSS services to help bridge the gap between disciplines and departments. During new employee orientation, new staff hires should meet with PSS staff and shadow their position to learn about the department first hand, as they do with providers in other departments.

Patient education and outreach. While staff education can help increase referrals to PSS and strengthen multidisciplinary, integrative cancer care, patient education and outreach is needed to ensure program services are reaching their intended audience. Although all patients to receive a paper-and-pencil screening for psychosocial distress meant to identify patients in need of outreach and support services, not all patients meet PSS staff or understand the full breadth of services available to them and their family members.

Patients expressed the need for more information on available program resources, both in print and in person. Similarly, PRCP staff requested program services be explained to patients more thoroughly or explicitly at the beginning of treatment. Because patients are initially focused on understanding their diagnosis and treatment options, information they receive upfront is heavily focused on treatment education and less on ancillary services. The general census of PSS

staff is to provide PSS outreach shortly after patients have had a chance to acclimate to their treatment schedule, presumably when they are better able to absorb additional information and consider adjacent services to support their cancer care. PSS is encouraged to consider delivering patient education in-person on a regular basis. A monthly “meet and greet” table can be set up in high traffic areas such as infusion or waiting rooms to increase PSS visibility and provide in-person education. Printed program materials can be easily advertised and distributed, and patients and staff alike can also become more familiar with PSS staff in a personable, informal manner. A meet and greet table also brings awareness and education directly to patients, quite literally meeting patients where they are rather than relying on them to seek out program services on their own.

Because patients receive oncology services on the second and third floor of the Cancer Partnership, services located on the first floor do not regularly receive foot traffic from patients. Additionally, many services aren’t easily noticeable as they occur behind locked doors, a part of the building not accessible to patients unless accompanied by staff. A team of receptionists and schedulers were previously staffed on the first floor, which drew greater attention to first floor services in general and also helped direct patients to services as needed. Reinstating staffing on the first floor of the building where ancillary services are housed may also increase visibility and awareness of program services and create a more engaging atmosphere on the first floor.

Marketing and advertising. The more marketing materials are made easily and readily accessible, the more patients and staff can be accurately informed of program services, eligibility (when appropriate), and how to reach PSS. In general, better marketing and up-to-date advertising may reduce confusion and inaccuracies in program services that have potentially led

to areas of dissatisfaction in the first place. Clearer and more accessible program information may improve patient education and help patients better utilize program services.

Marketing materials should be frequently monitored to ensure the most accurate information is being advertised. In addition to marketing materials being placed in highly visible locations throughout the Cancer Partnership, fact sheets answering frequently asked questions can be created and stored at nursing stations in infusion. Oncology nurses spend a great deal of time interacting with patients as they deliver chemotherapy and other treatments and, as such, nurses often screen patients for distress and serve as a primary point of contact for patients to learn about ancillary services. Nurses could easily distribute fact sheets with up-to-date information on frequently requested resources such as transportation services, Washington Medicaid Programs such as Community Options Program Entry System (COPES), and Social Security Disability Insurance Program (SSDI). Fact sheets would also serve to educate PRCP staff on resources that receive a great deal of attention within the Cancer Partnership and improve the working relationship between PSS and other departments creating a more cohesive experience for patients.

In addition to traditional marketing materials (i.e., business cards, flyers, printed brochures), PRCP should consider investing in television monitors that digitally display information about PRCP at large. Television monitors have the advantage of displaying a variety of information to a large audience rather than printed brochures that patients have to seek out on their own. Additionally, digital information can be easily updated or edited without having to reprint materials. Television monitors can be positioned in waiting areas or infusion where patients are gathered for long periods of time. Advertised information could include PRCP staff biographies and specialties, clinical research trials, upcoming events, and program services.

Program services can also be advertised while callers are placed on hold during telephone calls to PRCP.

Services and access. In general, patients expressed high satisfaction regarding the quality and variety of program services. However, transportation, hospice care, and family services were identified as areas in need of improvement.

Transportation. Satisfaction surveys demonstrated transportation services were a highly valued service and appeared to be well utilized by patients. In many instances, transportation services were rated as a program strength. Additionally, 63% of staff reported making referrals to PSS for patient transportation needs, indicating a highly visible service within the department.

PSS is advised to create handouts advertising available transportation services to clarify rider eligibility requirements and inform staff and patients how services can be utilized and arranged. Brief, fact-based handouts should be placed in high traffic areas such as infusion, waiting areas, and nursing stations for easy access and reference to available services. Because available transportation services are limited based on rider eligibility requirements, PSS is urged to consider allocating funds toward alternate transportation options to assist patients with transportation hardships. Funds could be put towards purchasing ferry tickets, bus fare, taxicab vouchers, or additional gas gift cards.

Concerns regarding transportation services may have more to do with available transportation services and rider eligibility requirements than deficits in how PSS utilize services. Further evaluation is recommended to determine specific areas of dissatisfaction within transportation services.

Hospice care. Patients receiving hospice care were marginally represented throughout this evaluation, despite Palliative Care having a strong presence at PRCP. Indeed, of the 152

patient surveys, only one respondent indicated receiving hospice care and two respondents reported involvement with Palliative Care. Nevertheless, providing compassionate end-of-life care is an essential component treating progressive illness and requires more attention than this evaluation could provide.

While advanced stage cancer represents a high percentage of all cancer cases at PRCP (19.7%) and, therefore, many patients who eventually face the final stages of their illness, it is unclear how well hospice care is utilized within the Cancer Partnership and what role PSS could provide in helping patients transition onto hospice. Further evaluation is recommended to better understand how and when referrals to hospice are made and how PSS might provide assistance.

Family services. Both patients and staff surveyed requested more support opportunities for family members and caregivers. Interestingly, the inclusion of family members in program services occurred quite frequently and organically. Indeed, 17% of single-use participants, 42% of multiuse participants, and 37% of group users involved family members in their care and PSS. However, data from the current evaluation did not distinguish family members who participated in program services for their own needs from those who participated in program services for the primary purpose of supporting the person affected by cancer. Effects of cancer on caregivers and family members are well documented (see IOM, 2008 for a review of relevant research), and as such, a strong argument can be made to ensure program services are offered explicitly for caregiver support.

Currently, PSS does not offer any resources explicitly for caregivers, though family members are welcome to participate in most program services including counseling and the majority of PSS support groups. A Caregiver Support Group previously existed, but has since been consolidated into a general support group due to low attendance numbers. Family members

do appear to be present among a variety of program services as indicated by utilization of services results, however, how family members utilize services and for what purpose remains unknown. PSS is encouraged to consider how family members and caregivers can be better supported through program services, both for their own benefit and to support loved ones going through cancer. Marketing materials should be modified to inform and encourage caregivers of support opportunities geared specifically towards them.

PSS staffing. Staffing concerns were the most frequently critiqued area within the department. Patients and staff identified PSS staffing concerns including staff training and consistency in care provided, staff access, and staff response time on urgent needs. Proposed recommendations focus on understanding staffing concerns based on the current model of care.

Staff training and consistency. Patients reported dissatisfaction with PSS staff training and education as well as inconsistencies receiving care from PSS staff. Training and consistency concerns may be related to the annual turnover rate of PSS staff given the department's reliance on psychology and social work interns to supplement PSS staffing. Current PSS staffing consists of a half-time psychologist who also serves as the medical director of program services and a social worker who is employed 32 hours per week. On average, one or two psychology interns join the department for a twelve-month contractual learning agreement to complete clinical training requirements. Modifications to PSS's internship training curriculum may address concerns regarding staff education and inconsistencies in care provided.

The Medical Director of Psychosocial Services is encouraged to create a standard training program with specific learning modules based on department needs to improve consistency and education among staff and interns. Procedural flow charts should be created to help staff identify available resources and program services based on the level of patient care needed. Examples

could include procedural diagrams on when and how to complete applications for Washington Medicaid Programs (i.e., Community Options Program Entry System, COPES), Social Security Disability Insurance Program (SSDI), and PRCP's Patient Assistance Fund for patients experiencing financial hardship.

Staff access. PRCP staff expressed critical feedback regarding PSS staffing access including staff availability, visibility throughout the Cancer Partnership, and lack of full-time staffing. Recommendations are proposed to improve accessibility and consider overall staffing conditions. Visibility concerns may be improved secondarily by addressing staff access as well as proposed recommendations to improve PRCP staff education, patient outreach, and program marketing, as previously discussed (see education and outreach section above).

PRCP staff indicated difficulty reaching PSS by phone during regular business hours and a request was made for PSS staff to be more available for referrals and immediate concerns. A centralized phone number is recommended to reach all PSS staff and, thereby, improve staff accessibility. Currently, two phone numbers exist for the department based on office staffing—one number reaches the designated social worker, while another number reaches interns and the Director of program services. A separate number is also utilized to reach staff by pager, for example when staff are outside the office visiting patients in infusion or patients hospitalized in an adjacent building. All PSS staff generally provide the same services and work in close proximity to one another, eliminating the need for two distinct phone numbers; a centralized phone number would likely improve accessibility and reduce confusion among staff trying to promptly reach PSS.

Again, it is worth noting that a good portion of PSS staffing is comprised of psychology interns, generally constituting at least half the department's staff. Specific requests were made by

PRCP staff to expand current PSS staffing conditions including first floor reception staff, a full-time social worker, and a full-time nutritionist or dietician. Because current staffing conditions affect available program services, satisfaction of services, consistency and quality of services provided, and department accessibility or visibility, the current staffing model should be further evaluated. More specifically, the long-term sustainability of PSS should be evaluated based on PSS's current staffing conditions and reliance on qualified psychology interns. Furthermore, the ratio of full-time PSS staff to all PRCP patients should be evaluated and compared to other cancer treatment programs to determine if PSS's current staffing model is similar and/or sufficient. It should be noted that since 2010, the Medical Director of Psychosocial Services has sought to identify ways to rely less heavily on students/interns and increase hiring practices for permanent staffing (K. Johnson, personal communication, 2013; PSS, 2010), recognizing the sustainability of quality, consistent staffing as an area of concern the past several years.

Response time. In addition to difficulty reaching PSS staff, PRCP staff indicated dissatisfaction with PSS response time on urgent matters such as calls, pages, and Distress Assessment questionnaires with marked levels of high distress. Additionally, results from the staff survey rated PSS staff's ability to triage patients with high acuity as a relatively low department strength, indicating a consistent concern from staff about how PSS attends to patients in high or immediate need. Interestingly, patient surveys indicated high satisfaction concerning both PSS staff access and responsiveness, reflecting differences among patient and staff perceptions.

Concerns regarding the immediacy of PSS staff responding to perceived urgent needs is an area that requires further evaluation. Poor response time on urgent matters may reflect a variety of concerns, for example understaffing, poor staff accessibility, or insufficient education

about how PRCP staff can use and access PSS resources. The fact that staff reported low satisfaction with PSS response time but patients did not indicate an interesting discrepancy between staff and patient perceptions, which is worth investigating. To better understand concerns, PRCP staff should be interviewed to identify specific areas of concern and how concerns may be addressed. Additionally, quality assurance measures should be reviewed to monitor response time on urgent referrals made by staff and Distress Assessment questionnaires to corroborate concerns. It is possible that recommended improvements regarding PSS staff accessibility and PRCP staff education may secondarily address response time concerns.

Stakeholder Feedback Sessions

Three feedback sessions were held to present evaluation findings and invite stakeholders to participate in how findings can be used to improve and advance program services. The intended audience of this evaluation was PSS staff who deliver program services as well as program administrators who have input in making overall program changes. Feedback sessions were tailored to the audience of each meeting and delivered in multiple formats to make information easily accessible and engaging (Fitzpatrick et al., 2004). In alignment with the collaborative methodology of program evaluations, stakeholders were intentionally and continuously involved in the entirety of this evaluation (Preskill & Jones, 2009) which undoubtedly shaped the usefulness and credibility of program findings and recommendations.

The first stakeholder feedback session was held during the quarterly Psychosocial Steering Committee, the same meeting where areas of evaluation interest were first generated the prior year. Nine staff members were present during the feedback session, including members of the management team (Executive Director of PRCP and administrative executive) as well as supporting specialists (Medical Director of Psychosocial Services, American Cancer Society

representative, and Patient Support Services clinical staff). A PowerPoint presentation outlined evaluation findings and identified areas for improvement. An informal follow up meeting was held during the weekly PSS meeting to further discuss areas of feedback and generate program recommendations. Six staff attended the follow up meeting representing the current PSS team entirely and a representative from ACS.

A final feedback session was held during the quarterly Cancer Executive Committee meeting, the forum for discussing organizational recommendations for strategic and business development. Program findings and proposed recommendations based on stakeholder input were presented to leadership as part of the dialogue on the growth and development of PRCP at large. Fourteen members were present including the Vice President and Chief Medical Officer of PRCP among physicians and administration representative of medical oncology, radiation oncology, diagnostic radiology, and surgery.

Evaluation Limitations

Several limitations of this evaluation and its methodology are noted. First, utilization of services data did not represent an exhaustive review of all patients who participated in program services nor all staff members who provided services. Patient names were selected for auditing based on staff charting records, July 2014–June 2015 for group participation and January–June 2015 for individual or family interaction. Four hundred chart audits were decidedly selected to allow for comparisons between groups—single-use participants, multiuse, and group users—though more chart audits could have easily occurred. Selecting electronic health records for review in this manner was somewhat arbitrary and neglected many people may have participated in program services. For example, data did not include men who attended the prostate cancer support group since it was not facilitated by PSS staff. Data also did not accurately capture

family members who received support services since there was no way to verify information or collect data using electronic health records unless family members were also oncology patients. In other instances, PSS may have provided services to persons with cancer who were treated outside PRCP; for example, support groups were open to all persons with cancer and attracted people who have/had received treatment elsewhere, but live near PRCP and chose to participate in program services. Again, unless an electronic health record was available for review, these persons were not included in the analysis. Data was also not available for patients who received services from the Medical Director of Psychosocial Services or the social work intern who began working with the department midway through this evaluation. It would seem there were many exceptions to how data was collected for chart review and, thus, results did not wholly encompass program participants. Had utilization of services represented all patients who used program services during a one-year span, more inferences could have been made generalizing how services were utilized and by whom. For example, it may have been useful to know how many patients were served by PSS compared to all new cancer cases at PRCP. Instead of a comprehensive and exhaustive analysis of program utilization, observed trends were noted and recommendations made for further evaluation as indicated.

The methodology used to collect survey data also contained shortcomings. For the most part, patient and staff surveys consisted of forced choice, Likert scales to easily capture respondents' attitudes and opinions and to identify trends based on positive or negative feedback. A substantial limitation to forced choice responses on surveys was the dearth of specificity captured in responses. While forced choice surveys may have encouraged a high response rate given the relative ease of completing surveys, they lacked specificity and detail in their responses. In this evaluation, it would have been helpful to have more information when patients

or staff indicated areas of concern. Specific examples or scenarios illustrating areas of concern or criticism may have helped better inform treatment recommendation and ensure future changes address areas of concern based on feedback. Interviews were not conducted to limit the scope of this evaluation, though future interviews could explore areas of feedback more thoroughly to provide a more in-depth analysis of perceived areas of strength and weakness.

While this evaluation focused specifically on services provided by Patient Support Services, other departments within integrative services were included in the data as well. Information about nutrition services, the Cancer Resource Center, and financial assistance were included given the proximity of those departments working with PSS. However, combining integrative services with PSS made it difficult to delineate which services were utilized and criticized at times. For example, some survey respondents indicated attending a support group, but listed the Look Good Feel Better class offered through the Cancer Resource Center, which is not facilitated by PSS staff. Additionally, financial assistance could refer to PSS staff helping patients apply for SSDI, completing an application for the Susan G. Komen breast cancer fund, or PRCP's financial assistance fund, or, alternately, could refer to assistance provided by PRCP's financial advisors who oversee insurance coverage and billing questions. Small distinctions in language may have also produced skewed results on survey questions. For example, the phrase "social work" was used to imply working with a PSS staff member to gather resources or help with financial assistance; however, respondents may have assumed that meeting with a social worker (verses psychologist or intern) for any reason (i.e., emotional support, family counseling) was "social work," thus misrepresenting the services actually used. Respondents may have also struggled to differentiate between "emotional support during treatment" (meant to convey services received during infusion, radiation, or hospitalization) from "counseling" (meant to

convey individual or family psychotherapy or counseling generally received in the office).

Again, a clear limitation of using surveys to collect data was that respondents were unable to ask for clarification and the evaluator was unable to ask respondents any follow up questions.

A final limitation of this evaluation was its intended scope. From the beginning, this formative evaluation sought to evaluate a *part* of PSS, not the summation of program services. Therefore, limitations of this evaluation were inherent given the finite scope of services reviewed for feedback. In the future, a summative evaluation may be conducted to further assess PSS's value and to help program personnel make decisions concerning the program's continuation or expansion (Fitzpatrick et al., 2004). Lastly, while this evaluation identified program strengths and recommendations to address areas of improvement, the organization is responsible for deciding whether to implement recommendations and to use evaluation findings as one tool in understanding and enhancing program services.

Conclusion

This program evaluation provided an overview of psychosocial services as they are utilized and valued by patients and staff. Nine years since the inception of Providence Regional Cancer Partnership, this evaluation took a first look at how Patient Support program services were utilized and by whom. Results identified program strengths indicated by areas well represented by patients. Patients with advanced stage cancer were highly represented among program participants as well as patients with presumed financial distress. Program recommendations were provided to improve areas underutilized and underrepresented by patients, in particular identifying the need to diversify program services to more closely reflect expected gender and cancer demographics compared to national prevalence rates (NCI, 2016)

and PRCP population statistics. Additionally, a proposal was made to further evaluate support groups based on utilization trends and mixed feedback.

In addition to program utilization data, satisfaction surveys were distributed for the first time since 2009 providing feedback concerning areas of satisfaction and dissatisfaction. Survey data revealed many program areas of strength and satisfaction including the department's ability to provide emotional support, high quality and variety of program services, and the program's overall value as part of a larger cancer treatment center. Areas for improvement were categorized into three themes reflecting shared concerns: patient education and outreach, program services and access, and PSS staffing. Thoughtful and informed recommendations were presented with collaboration from stakeholders to improve program services and further benefit PRCP's patient population. Upon implementing recommendations, PSS may see remarkable differences in more than one area identified as a concern. For example, concerns regarding staff access and visibility may be resolved secondarily by improvements made to PRCP staff education, patient outreach, and program marketing.

In general, this evaluation clarified areas of strength and areas recommended for improvement. During multiple stakeholder meetings, feedback was provided about the general efficacy of program services and the merit of Patient Support Services within the larger Cancer Partnership. Subsequently, results of this evaluation validated staff efforts to enact the mission of PSS: To provide psychosocial services to some of PRCP's patients in greatest need. Results from this evaluation can be referred to throughout the program's existence to monitor PSS's adherence to the program's goals and mission and to continue assessing its efficacy in providing program services that are well utilized and valued.

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Appendix A

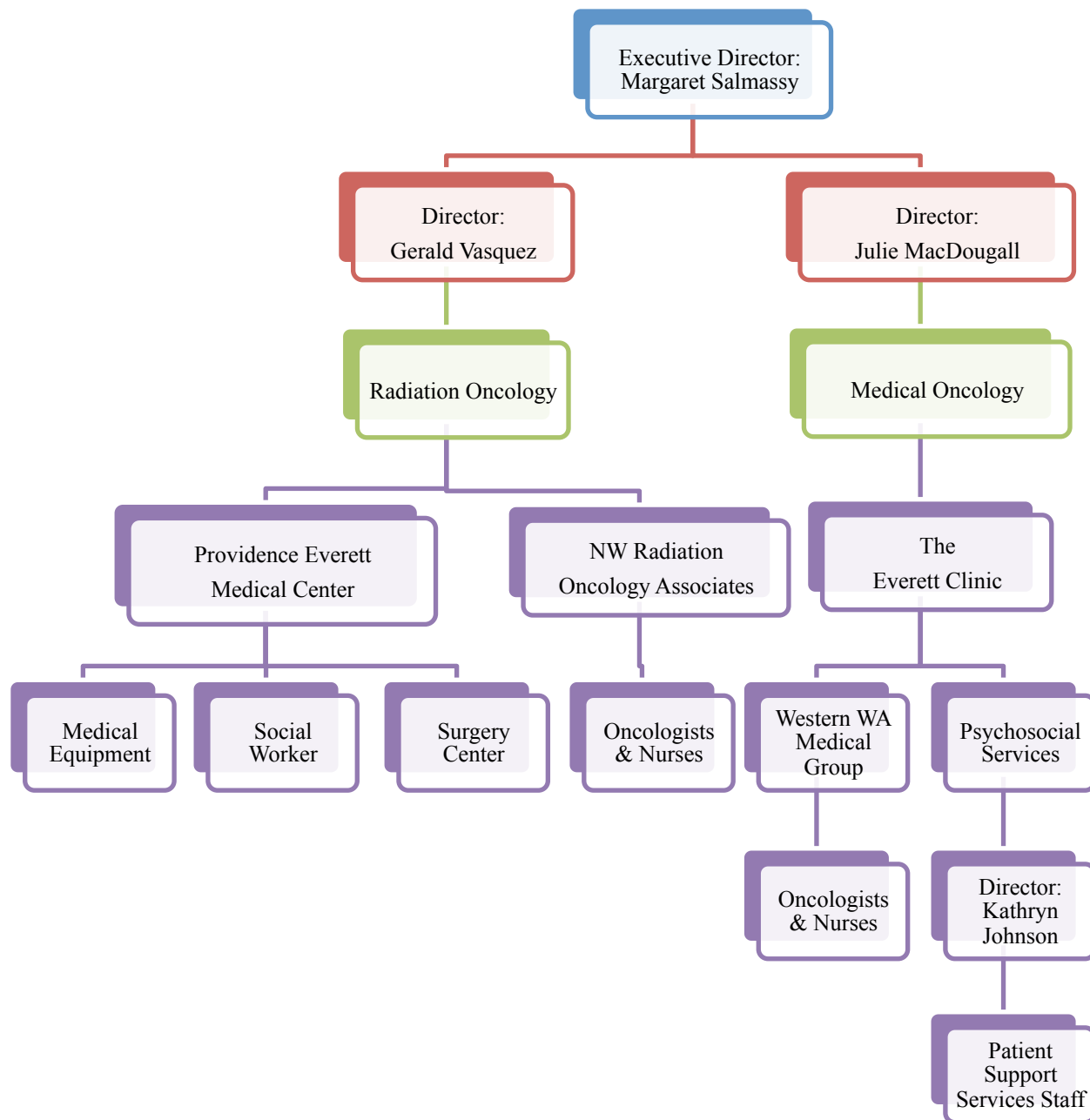
NCCN Standards of Care for Distress Management

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.
- Screening should identify the level and nature of the distress.
- Ideally, patients should be screened for distress at every medical visit as a hallmark of patient-centered care. At a minimum, patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status (i.e., remission, recurrence, progression, treatment-related complications).
- Distress should be assessed and managed according to clinical practice guidelines.
- Interdisciplinary institutional committees should be formed to implement standards for distress management.
- Educational and training programs should be developed to ensure that health care professionals and certified chaplains have knowledge and skills in the assessment and management of distress.
- Licensed mental health professionals and certified chaplains experienced in psychosocial aspects of cancer should be readily available as staff members or by referral.
- Medical care contracts should include reimbursement for services provided by mental health professionals.
- Clinical health outcomes should include assessment of the psychosocial domain (e.g., quality of life and patient and family satisfaction).
- Patients, families, and treatment teams should be informed that distress management is an integral part of total medical care and provided with appropriate information about psychosocial services in the treatment center and the community.
- Quality of distress management programs/services should be included in institutional continuous quality improvement (CQI) projects.

(NCCN, 2016b, p. DIS-3)

Appendix B

Providence Regional Cancer Partnership Organizational Chart



Appendix C

Providence Regional Cancer Partnership Services Provided

Diagnostic Imaging

Angiography
 Bronchoscopy
 Computerized Axial Tomography Scan
 Digital Radiography for Mammography
 Echocardiography
 Electromagnetic Navigational Bronchoscopy
 Low-dose CT Screening
 Magnetic Resonance Imaging
 Magnetic Resonance Mammography
 Mammography
 Mediastinoscopy
 Nuclear Medicine
 Positron Emission Tomography Scan
 Stereotactic Guided Biopsy
 Ultrasound

Clinical Research

Prevention
 Quality of Life
 Screening
 Treatment

Medical Oncology

Biotherapy
 Chemoembolization
 Hormone Therapy
 Immunotherapy
 Infusion Center with Chemotherapy
 Plasmapheresis

Surgery

Cryosurgery
 da Vinci Robotic Assisted Procedures
 DIEP Flap Breast Reconstruction
 Laparoscopic Surgery
 Limb Infusion
 Mammosite
 Microwave Ablation
 Sentinel Lymph Node Biopsy
 Ultrasonic Surgical Aspiration
 Video Assisted Thoracic Surgery

Radiation Oncology

3D Conformal Radiation Therapy
 Brachytherapy (High Dose Rate)

Brachytherapy (Low Dose Rate)
 Computerized Treatment Planning
 Electron Beam
 External Beam Radiation Therapy
 Extracranial Radiosurgery
 MammoSite Radiation Therapy
 Image-Guided Radiation Therapy
 Intensity Modulated Radiation Therapy
 Linear Accelerator
 Prostate Seed Implant
 Respiratory Gating
 Stereotactic Radiosurgery
 Systemic Radioisotopes

Support Services

Acupuncture
 Advanced Care Planning
 Art Therapy
 Breast Pain Clinic
 Cancer Resource Center
 Caregiver and Family Counseling
 Classes and Support Groups
 Distress Assessment
 Integrative Medicine Services
 Fertility Counseling
 Financial Counseling
 Genetic Counseling and Testing
 Healing Spirit Boutique
 Home Care Program
 Hospice
 Lodging Assistance
 Mastectomy Education
 Mind-Body Medicine
 Naturopathic Medicine
 Nutrition Counseling
 Pain and Symptom Management
 Palliative Care Services
 Pastoral Care
 Patient Navigator Program
 Prosthetic Services
 Rehabilitation Therapy
 Smoking Cessation Program
 Survivorship Program
 Transportation Assistance
 Wellness Program
 Wound Care Clinic

(PRCP, 2014)

Appendix D

Providence Regional Cancer Partnership Incidence of Cancer by Site and Gender

Primary Site	# of Cases	Male	Female
Brain	33	21	12
Cranial nerves & nervous system	47	16	31
Oral cavity & pharynx	40	35	5
Esophagus	26	20	6
Larynx	9	7	2
Thyroid	44	19	25
Other endocrine	20	9	11
Lung	275	142	133
Mesothelioma	4	4	0
Breast	370	2	368
Liver & intrahaptic bile duct	25	16	9
Stomach	20	13	7
Pancreas	36	15	21
Kidney & renal pelvis	56	39	17
Small intestine	4	4	0
Colon	89	47	42
Bladder	92	71	21
Rectum & rectosigmoid	58	36	22
Anus, anal canal, anorectum	9	1	8
Cervix uteri	21	--	21
Corpus uteri	94	--	94
Ovary	35	--	35
Vulva	13	--	13
Prostate	105	105	--
Testis	17	17	--
Leukemias	47	15	7
Lymphomas	82	50	42
Multiple myeloma	24	17	7
Melanoma	64	28	36
Soft tissue	6	4	2
Other	139	84	70
TOTAL	1,904	837	1,067

Appendix E

Providence Regional Cancer Partnership Incidence of Cancer by Site and Stage

Primary Site	Stage I	Stage II	Stage III	Stage IV
Oral cavity & pharynx	2	1	4	32
Esophagus	9	2	6	9
Larynx	3	2	1	3
Thyroid	24	3	9	7
Lung	71	29	40	134
Mesothelioma	1	1	0	1
Breast	160	112	31	12
Liver & intrahaptic bile duct	6	4	4	10
Stomach	5	3	4	8
Pancreas	3	7	2	23
Kidney & renal pelvis	30	6	8	9
Small intestine	0	0	2	2
Colon	20	24	20	22
Bladder	19	10	4	9
Rectum & rectosigmoid	12	17	13	13
Anus, anal canal, anorectum	5	2	1	0
Cervix uteri	10	3	4	3
Corpus uteri	74	3	9	7
Ovary	5	7	16	6
Vulva	7	0	0	2
Prostate	16	53	20	16
Testis	17	0	0	0
Lymphomas	23	19	16	34
Melanoma	32	12	7	3
Soft tissue	3	1	1	1
Other	4	5	12	9
TOTAL	561	326	234	375

Appendix F

Providence Regional Cancer Partnership Incidence of Cancer by Site and Primary Payer Report

Primary Site	Private	Medicaid	Medicare
Brain	19	3	11
Cranial nerves & nervous system	18	3	23
Oral cavity & pharynx	24	1	12
Esophagus	11	0	15
Larynx	4	2	3
Thyroid	31	2	11
Other endocrine	9	3	7
Lung	68	19	185
Mesothelioma	1	0	3
Breast	189	34	147
Liver & intrahaptic bile duct	4	3	18
Stomach	11	0	9
Pancreas	10	3	23
Kidney & renal pelvis	17	3	35
Small intestine	1	1	2
Colon	37	5	47
Bladder	26	5	60
Rectum & rectosigmoid	27	2	27
Anus, anal canal, anorectum	2	1	6
Cervix uteri	13	3	5
Corpus uteri	29	10	52
Ovary	13	3	18
Vulva	0	1	12
Prostate	37	8	57
Testis	11	2	0
Leukemias	16	3	27
Lymphomas	30	9	52
Multiple myeloma	4	2	18
Melanoma	28	4	31
Soft tissue	4	0	2
Other	31	7	84
TOTAL	725	142	1,002

Appendix G

Psychosocial Services Policy and Procedures: Access to Psychosocial Services

PURPOSE

The purpose is to ensure that all patients, family members, and caregivers have access to psychosocial services. Psychosocial services are essential components of comprehensive cancer care and are provided to patients with cancer and their caregivers throughout the continuum of care. These services address physical, psychological, social, spiritual, and financial support needs that result from a cancer diagnosis and help ensure the best possible outcome.

PSYCHOSOCIAL SERVICE PROVIDERS

A variety of psychosocial services are available on-site, most at no cost, to all patients and their caregivers. These services are provided by the following disciplines:

- Chaplain
- Psychologist
- Clinical social worker
- Registered dietician
- Interns in the fields of clinical psychology and social work
- Financial counselors
- Clinical nurse specialist
- American Cancer Society volunteers

POLICY

- All patients, family members, and caregivers have access to the full range of psychosocial services
- Individuals who are not receiving treatment at PRCP are also welcome to attend the support groups and classes at PRCP
- Patients may be referred for services by their physician, nurse, or any staff member
- Patients and caregivers may self-refer for all groups, classes, and individual services
- If the needed service is not available on-site, Patient Support staff will provide appropriate community referrals
- Both on-site and community resources are available on the PRCP website. Brochures and flyers outlining the available services are available and displayed on each floor of the Cancer Partnership, as well as in the Cancer Resource Center
- Each patient's needs for services are routinely monitored through the use of the distress assessment tool
- Once a need is identified, the patient will be informed of available services either by phone, in person, or by mail

DOCUMENTATION

- Support group attendance is reported monthly to the Cancer Partnership administration
- Individual services are documented as notes in the patient's electronic health record

AVAILABLE GROUPS AND RESOURCES

The following is a list of services typically available on-site. Specific groups are subject to change based on the current needs and requests of patients at any given time.

- Supportive counseling
- Support groups
- Assistance with resources
- Spiritual support
- Assistance with Advanced Directive, Living Will, and Durable Power of Attorney for Health Care
- Nutritional counseling
- Financial counseling and assistance for uninsured and underinsured patients

(PRCP, 2012c)

Appendix H

Providence Regional Cancer Partnership Support Resources

Support resources add an extra dimension of care to fight your cancer and promote your health on every level—body, mind and spirit. You can count on the attention and knowledge of leading practitioners in their fields who are devoted to helping you feel better and get better.

Cancer Resource Center

The Cancer Resource Center is a quiet, comfortable place for patients, families and caregivers to find information on cancer, log on to the internet, or talk with a Patient Navigator or volunteer. It's also a convenient source for the latest information on cancer tests, treatments, clinical trials, and local resources for support groups and transportation services. A wide variety of literature on cancer and treatment is here for you, free of charge.

Patient Navigator

At the Cancer Partnership, you'll have a Patient Navigator who is dedicated to answering questions, providing resources and suggesting support services throughout your treatment and beyond. This highly-trained cancer expert is part of the American Cancer Society Patient Navigator Program, a respected network that follows national standards, offers extensive training, and serves patients at more than 60 sites around the country.

The Patient Navigator is here to listen, care and help, so you never have to wonder where to turn. You can count on your Patient Navigator to:

- Provide information on what to expect during chemotherapy and radiation, and on dealing with any side effects of treatment.
- Share resources with you for financial assistance, medication needs, home health care, insurance, transportation and other concerns.
- Refer you to groups, classes and support programs.
- Connect you with helpful resources in your community.
- Suggest activities that can help ensure a better quality of life both during and after treatment.

Healing Spirit Boutique

The Healing Spirit Boutique is a special place in the hearts of many cancer patients. It is here to provide free hats, wigs and understanding to patients experiencing appearance-related changes during cancer treatment. The boutique is staffed by volunteers who are experienced in finding and fitting the right style and hair color of wig, along with complementary cosmetics.

Classes

Classes at the Cancer Partnership are open to all patients, family members, friends and caregivers. They're a great way to build your support network and engage in the healing process with others who understand. Classes are also open to the general public and to cancer patients who are not patients of the Cancer Partnership.

Art therapy

Art therapy increases your awareness of yourself and others and is a great therapeutic tool for cancer patients. It is fun and life-affirming, and enhances cognitive abilities. This class offers a supportive, non-judgmental environment, and no artistic ability is

required. Our art therapists, trained in both art and therapy, offer guidance and support, as well the opportunity to explore a variety of art materials.

Gentle yoga

Reconnect with your body and learn how to be gentle with yourself in a fun, noncompetitive environment. Wear comfortable clothes, and bring a mat and water bottle. This non-aerobic form of exercise concentrates on movements and deep breathing. It can help reduce stress and fatigue, as well as improve sleep. Exercise promotes healing and well-being during cancer treatment and can help accelerate your long-term recovery process.

Look good. Feel better.

The name of this unique program says it all. Sponsored by American Cancer Society, it's designed for women going through the effects of cancer treatment. Classes focus on skin and hair care, cosmetics, wigs and head wraps, dealing with hair loss, and getting healthy nutrition. Cosmetic samples and makeovers are available. All cosmetic products for your makeover are complimentary and provided for you to enjoy and take home with you.

Nutrition

Learn about the foods that can strengthen your immune system, improve your energy, and maintain a healthy weight. Our free monthly nutrition class is dedicated to helping patients, survivors, family members and other caregivers improve their health through better eating.

Counseling Services

When you receive a cancer diagnosis, it's natural to have questions and concerns. You may also need some extra support for yourself and your loved ones. After all, a cancer diagnosis affects everyone in the family in many ways.

Our Patient Support Services Team is available by appointment to provide one-to-one counseling and help you address any of the following concerns:

- Coping with a new diagnosis, treatment or recurrence
- Creating a care team at home
- Family communication
- Support in making difficult treatment decisions
- Self-care for patients and caregivers
- Stress management
- Identifying resources
- Anxiety and depression
- Grief and loss
- Survivorship concerns
- End of life concerns

Individual, group, and family counseling services are also available at no cost to Cancer Partnership patients and family members. Counseling services are provided by Masters-level trained clinicians working closely with cancer patients and their families. They're good listeners

and problem-solvers who are here to address the psychological, social, cultural, financial and continuing care needs of you and your family.

Financial Counseling

We believe everyone should have access to quality healthcare. If the financial side of cancer treatment is a worry for you, we encourage you to talk with our financial counselors. Financial counselors verify benefits, help develop a payment plan for treatment, and obtain outside assistance if necessary.

Patient Assistance Fund

The Linda Baltzell Patient Assistance Fund (PAF) was established in 1978 for patients who needed financial support, particularly paying their medical bills while they were receiving radiation treatments. The PAF today supports Cancer Partnership patients who are receiving chemotherapy and/or radiation and need financial assistance with rent, gas, groceries, medication, clothing, etc. (PRCP, 2015a).

Integrative Medicine

Integrative medicine offers a unique approach to healing. Services include a variety of complementary treatment options so patients are able to achieve maximum benefit and symptom relief. Care is coordinated with patient's chemotherapy and radiation treatment (PRCP, 2014).

Naturopathic Medicine

Naturopathic medicine is based on the knowledge that the human body has a natural healing ability, and that much can be done to enlist it in your care. Naturopathic doctors work with their patients to use diet, exercise, lifestyle changes and leading-edge natural therapies to improve their bodies' ability to combat disease and decrease side effects of treatment. Naturopathic services include:

- Nutrition
- Natural medicines (vitamins, minerals, botanicals)
- Acupuncture / Acupressure
- Risk reduction for cancer recurrence
- Re-establishing health
- Counseling

Nutrition Counseling

Nutrition counseling is provided for specific disease and symptoms to decrease the side effects of treatment. Vitamins and supplements are also addressed.

Acupuncture

Of all the support services we offer, acupuncture is one of the most often requested. For many of our patients and their referring oncologists, it plays a valuable role in addressing cancer from every angle. Studies show that acupuncture can help relieve cancer's symptoms and the side effects of treatment, including nausea, vomiting, fatigue and stress.

We make the best acupuncture available to you through our collaboration with Bastyr University, a national leader in natural health arts and sciences education and research. If you're interested in making acupuncture part of your personal treatment plan, please talk with your doctor or nurse.

Mindy-Body Medicine

Mindy-Body medicine is a field of medicine that uses the powers of the mind to enhance physical and emotional health. Patients learn to use the mind's healing abilities to relieve stress, manage symptoms, help with sleep, and restore mind, body, and spirit. Hypnosis, biofeedback, and relaxation techniques are taught.

Wellness Consults

Wellness consults are provided through the naturopathic medicine provider. Learn what steps to take after you are finished with treatment to return to wellness.

Language Support

For patients and their families who speak little or no English, we offer a toll-free telephone interpreter service. We invite patients to use this service to make appointments and related phone calls. Family members may use the service to call a loved one who is a patient in the hospital.

Palliative Care

Palliative care is dedicated to managing disease and treatment-related symptoms that help preserve quality of life for patients during all stages of serious illness. Our Palliative Care team includes nursing support through Partners in Palliative Care, together with medical care from our Palliative Care physician and Advance Registered Nurse Practitioner. These clinicians work together with your oncologist and the Patient Support Services Team to provide comprehensive care for the physical, emotional and spiritual needs of you and your family—always with your permission and your input. Palliative care is here to help in many ways, including:

- Managing pain and other symptoms
- Improving communication with your health care team, if needed
- Identifying goals of care
- Providing information about Advanced Directives
- Addressing home care needs
- Maintaining quality of life

Spiritual Care

Spirituality means different things to each of us—but for many people, it's an essential part of getting through a difficult time in life.

The chaplains at the adjacent Providence Regional Medical Center are available to help you through any emotional or spiritual aspects of your treatment. Professionally trained and board-certified, they are great listeners who do everything possible to support you and your family regardless of your religious beliefs. We strongly believe in respecting the cultural and spiritual diversity of those we serve.

Support Groups

Studies show what cancer patients know from their own personal experience: A support group can often play a valuable role in helping you feel better and get better. A good support group can be a powerful source of information, help, encouragement and understanding throughout your cancer treatment—for you and your loved ones. We offer a number of free, ongoing support groups here.

Retrieved from <http://www.cancerpartnership.org/Support-Resources.aspx>

(PRCP, n.d.)

Appendix I

Patient Support Services: Classes and Support Groups

Art Therapy Group

Art therapy increases your awareness of yourself and others and is a great therapeutic tool for cancer patients. It is fun and life-affirming, and enhances cognitive abilities. This class offers a supportive, non-judgmental environment, and no artistic ability is required. Our art therapists, trained in both art and therapy, offer guidance and support, as well the opportunity to explore a variety of art materials.

Women with Cancer Support Group

Previously the Breast Cancer Support Group

A support group for women who have or have had cancer. Connect with other women to maintain a positive focus and self-image and to build a support network. Topics include coping and relaxation strategies, breast cancer education, adjusting to change and guest speakers on a variety of topics.

Breast Cancer Support Group

For breast cancer patients and survivors to connect with each other and to maintain a positive focus and self-image, building a support network, and learn coping and relaxation strategies.

Young Breast Cancer Support Group

A support group for women who have or have had breast cancer. This group is target at women who are in their 20's, 30's, and 40's. Facilitated by an Oncology Social Worker.

Gentle Yoga

Reconnect with your body and learn how to be gentle with yourself in a fun, noncompetitive environment. This non-aerobic form of exercise concentrates on movements and deep breathing. It can help reduce stress and fatigue, as well as improve sleep. Exercise promotes healing and well-being during cancer treatment and can help accelerate your long-term recovery process. Facilitated by oncology yoga instructors. First five sessions are free.

Look Good... Feel Better

Sponsored by the American Cancer Society, this class is designed for women going through the effects of cancer treatment. The class focuses on skin and hair care, cosmetics, wigs and head wraps, dealing with hair loss, and getting healthy nutrition. Cosmetic samples and makeovers are available. All cosmetic products for your makeover are complimentary and provided for you to enjoy and take home with you. Registration required.

Nutrition Class

Learn about the foods that can strengthen your immune system, improve your energy, and maintain a healthy weight. Our free nutrition class is dedicated to helping patients, survivors, family members and other caregivers improve their health through better eating. Facilitated by a registered dietician.

Man-to Man Prostate Cancer Support Group

This group offers education and information sharing exclusively for men who have been diagnosed with, or who have had, prostate cancer. Facilitated by a cancer survivor contracted by Providence Regional Medical Center.

Support Group for Cancer Patients and Survivors

Combines two previous support groups: Caregiver Support Group and Support Group for Patients with Metastatic Disease

This support group is open to all cancer patients and survivors who have been diagnosed with any type of cancer. Members offer each other comfort, support, information, and suggestions for coping with potential challenges during and after treatment. Discussions may include developing a resiliency plan, work issues, designing a holistic health plan, finding hope and meaning, adjusting to effects of treatment, and building a support network.

Caregiver Support Group

This group teaches caregivers how to support someone with cancer while still taking care of themselves. Make time for yourself, maintain a positive focus, build a support network, learn coping and relaxation strategies, and more.

Support Group for Patients with Metastatic Disease (Advanced Cancer)

This group focuses on living with cancer and what it means to have metastatic disease. The discussion includes topics such addressing pain and other symptoms, increasing quality of life, managing treatment's late effects, talking to your family, getting the help you need, and interpreting medical information.

Tai Chi Self-Cultivation

Re-experience your mind and body through the practice of relaxing meditative movements. Participants will also receive information and learn how to promote self-care through positive psychology.

Survivorship Series Program

This eight-week services will give you ideas on maximizing your resources and strengths to help you adjust to life after treatment. As part of your own health care team, you will be given the opportunity to identify a wellness plan that is best for you. Registration required.

(PRCP, 2015b)

Appendix J

Psychosocial Services Policy and Procedures: Psychosocial Distress Screening

PURPOSE

To comply with Standard 3.2, American College of Surgeons, Commission on Cancer. The importance of screening patients for distress and psychosocial health is a critical step in providing high-quality cancer care. The purpose of this policy is to assure that distress is recognized, monitored, documented and treated promptly at all stages of the disease. A standard process is in place to incorporate distress screening into the standard of care for oncology patients and provide patients identified with distress with appropriate resources or referrals.

The Medical Director of Psychosocial Services oversees this activity and reports to the cancer committee annually.

PROCESS

Timing of Screening and Method

All patients diagnosed with cancer who seek treatment at PRCP are screened for distress a minimum of one time per treatment episode, although multiple screenings are scheduled for each patient. Due to the differential nature of radiation and chemotherapy treatment protocols, a distress screening protocol was developed for each. A standard patient questionnaire is used with all patients. If a patient is unable to read or use the paper form for any reason, clinical staff will verbally administer the screening.

Radiation Oncology patients receive the distress assessment the day of their intake appointment with the nurse. This is completed with the nurse intake. The front desk receptionist gives the form to the nurse who reviews it and incorporates it into the nurse intake. The nurse then initials the distress assessment and puts it in the patient support box at the front desk. Patient Support staff review the distress assessment forms daily, take necessary action, then take the forms to medial records to be scanned into the patient's chart.

Medical Oncology patients receive a distress assessment each time they are scheduled for both an office visit with a provider (MD, ARNP, or PA) and infusion treatment. The front desk receptionist gives the form to the patient to fill out in the reception area. The patient gives the completed distress assessment form to the medical assistant who documents the level of distress in the medial record and leaves the completed form for the provider to incorporate into their visit. The form is then put into the patient support box at the nursing station. Patient Support staff review the distress assessment forms daily, take action, then take the forms to be scanned into the patient's chart.

Tools

A distress measure was developed based on the NCCN Screening Tool for Measuring Distress. Patients who meet the following criteria using this measure receive further evaluation for follow-up care:

- Distress rated at or above 5 on a 1–10 scale (unless the box marked “No follow-up is needed at this time” is checked)
- Emotional, spiritual, family, or other concerns checked (unless the box marked “No follow-up is needed at this time” is checked)
- Any level of distress if the patient checks the box stating “I wish to be contacted regarding my concerns”

Assessment and Referral

If there is evidence of moderate or severe distress, as determined by the distress assessment questionnaire or by a member of the oncology team, further assessment will be done by a member of the Patient Support team within 72 hours. Assessment is done to determine if there are any psychological, behavioral, social, practical, financial, or spiritual problems that might interfere with the patient's ability to participate fully in their healthcare and adequately manage their illness.

Distress assessment questionnaires are collected each day and patients identified as needing follow-up are contacted either in person or by phone. In some instances patients are not contacted directly but are mailed information if they identify low levels of distress but indicate a desire for more information about specific supportive services such as available classes or support groups.

If the patient is in severe distress and needs to see someone immediately, any staff member may call the patient support pager. A patient support staff member will respond and assess the need for service.

Documentation

Distress screening and follow-up is documented in the patient's medical record. The distress assessment form is scanned into the record. All contact with patients, whether in person or by phone, are documented as clinical notes.

COMPLIANCE

A quality measure has been established to assure that patients are screened for distress. Each month a sample of at least 30 new treatment patients are identified. Each patient's medical record is reviewed for documentation of a distress screening within 30 days of the start of a treatment episode. The standard is that 95% of new treatment patients will have a documented distress screening within 30 days.

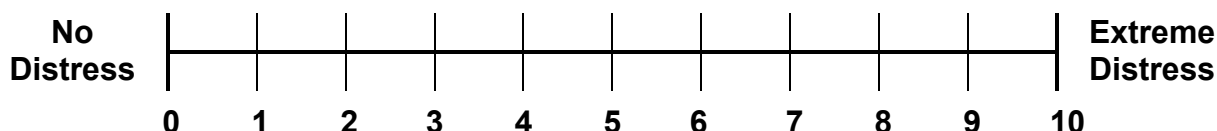
(PRCP, 2012b)

Appendix K

Providence Regional Cancer Partnership Distress Assessment Tool



Please circle the number that best describes how much distress you have been experiencing in the past week including today.



- I wish to be contacted regarding my concerns
 No follow up needed at this time

Practical Concerns

- Insurance
- Unable to pay bills
- Legal (POA, living wills, etc)
- School/Work
- Transportation
- Housing
- Child care
- Chores
- Bathing/dressing
- Sleep
- Respite care

Emotional Problems

- Depression
- Fears/Worry
- Nervousness
- Sadness
- Loss of interest in usual activities

Other problems or concerns _____

Family Problems

- Dealing with children
- Dealing with partner
- Intimacy/Sexuality

Spirituality

- Spiritual support
- Questions of faith

I would like information about:

- Social Security benefits
- Medicaid benefits
- Medicare benefits
- Nutrition
- Exercise & movement
- Hospice
- Support groups
- Other _____

Appendix L

Providence Regional Cancer Partnership Committees Supporting Goals

Multidisciplinary Cancer Committee (MDCC)

Chair: Elie Saikaly, MD

Meets quarterly and is charged with ensuring compliance with ACoS standards for all the Cancer Programs.

Multidisciplinary Cancer Committee Quality Assurance (MDCC QA)

Chair: Elie Saikaly, MD

Meets quarterly and is charged with ensuring, tracking, and reporting of all quality assurance and improvement activities for all the Cancer Programs.

Cancer Executive Committee

Chair: Elie Saikaly, MD

Meets monthly as the strategic and business development forum for the Cancer Program.

Integrative Medicine Committee

Chair: Cheryl Beighle, MD

Meets quarterly to educate and develop programs for patients.

Lung Task Force

Chair: Kimberly Costas, MD

Meets monthly to identify and implement multidisciplinary best practices for lung cancer patients to reduce time from diagnosis to treatment.

Medical Directors Meeting

Chair: Elie Saikaly, MD

Meets quarterly to oversee the operational management of the Cancer Partnership.

Psychosocial Committee

Chair: Kathryn Johnson, PhD

Meets quarterly to plan and implement program and service development to meet cancer patients' psychosocial needs.

Survivorship Steering Committee

Chair: Dawn Dickson, MSW, LICSW

Meets quarterly to plan and implement a Survivorship Program offered at Providence Regional Cancer Partnership

(PRCP Annual Report, 2012a)

Appendix M

Proposed Program Evaluation of Patient Support Services Stakeholder Brainstorming Meeting

The following summary information was generated during an initial brainstorming meeting with identified stakeholders during PRCP's fall quarterly Psychosocial Steering Committee meeting.

ATTENDEES

Kathryn Johnson, PhD, Julie MacDougall, Kelly Mardesich, RN, Kathy Reiff, Elie Saikaly, MD, Margaret Salmassy, Gerald Vasquez, Justine Colombo, MSW, Mary Jo Sarver, RN, Carrie Pilger, and Kristoffer Rouse

PRCP VISION

“A comprehensive, regional, state-of-the-art, single destination designed exclusively for the cancer patient and family with integrated and seamless clinical, operational and business processes.”

PROGRAM EVALUATION

Definition

Program Evaluation addresses professional issues through the use of evaluation design, problem formation, methodology, analysis of relevant quantitative and/or qualitative data, and report of findings in a constructive fashion. It may include questions pertaining to program utilization, implementation, fine-tuning, and effectiveness.

Purpose

To judge the merit or worth of a program and provide information for program improvement. Audience is generally people delivering the program or people who are in a position to make changes in the program and its day-to-day operations. Questions typically asked: What is working? What needs to be improved? How can it be improved?

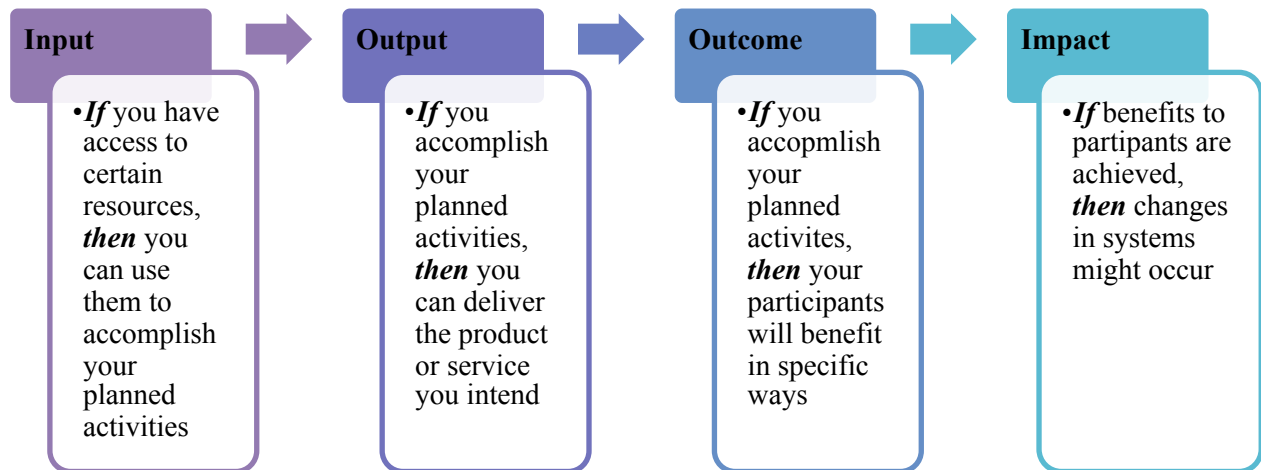
BRAINSTORMING PHASE

What aspects of the program should be evaluated? From a patient perspective, what should be evaluated?

- Elie: What is the purpose and value of PSS? Can a new intervention be added to PSS?
- Justine: What is the current patient experience? How do program services affect staff members? What is the cost and/or time savings on providers and the institution as a result of PSS?
- Mary Jo: What is the utilization of services among different types of cancer?
- Margaret: How does PRCP compare to other Providence cancer programs?
- Kathryn: How effective is the model of care based on current staffing? How does our model of care compare to other cancer programs? What is the difference between people who receive program services and those who do not? Is our mission still accurate? Are we doing what we said we would and are we doing it well?

Appendix N

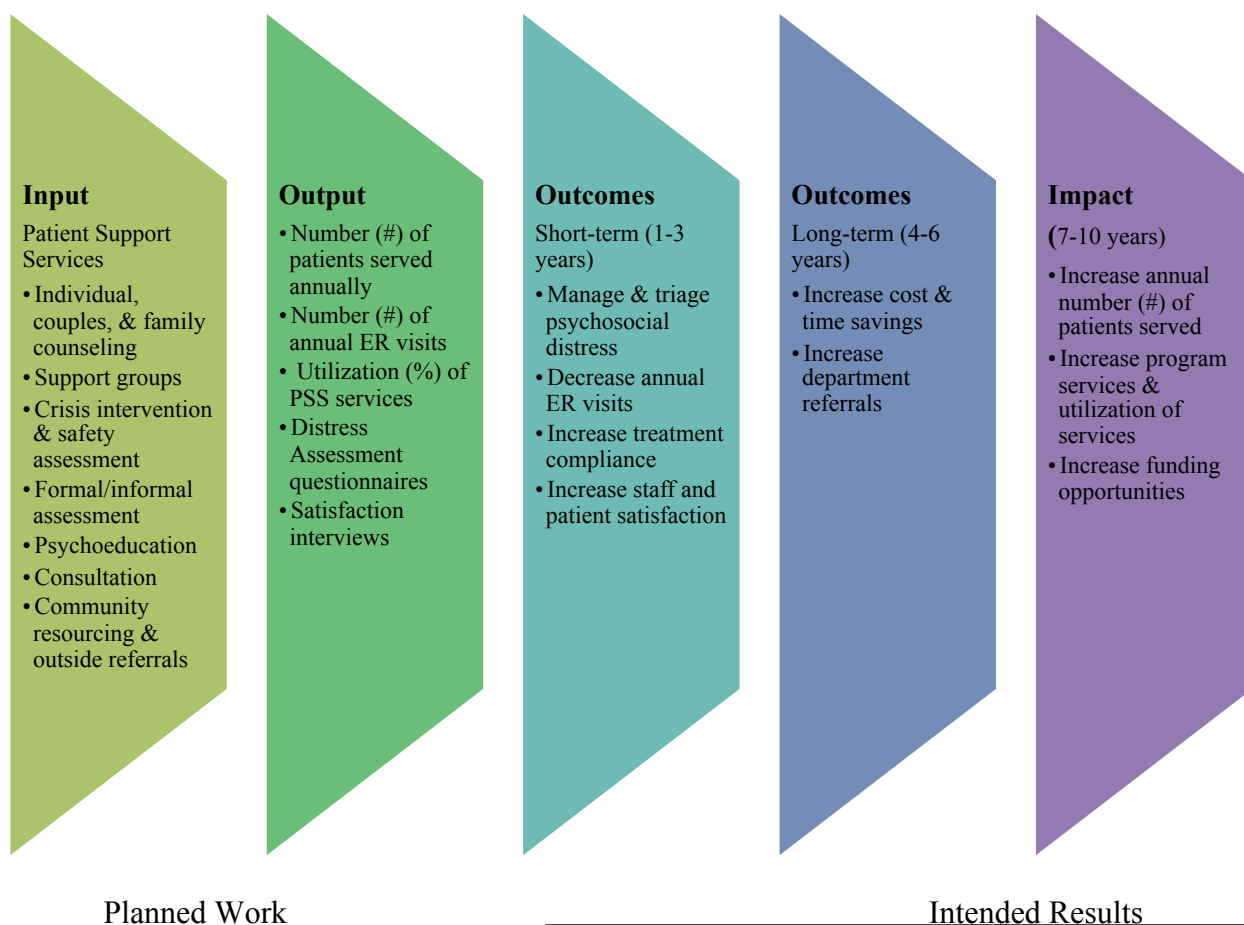
Logic Model: If...Then Assumptions



Note. From “Logic Model Development Guide” by W. K. Kellogg Foundation, 2004b, p. 3. Reprinted with permission.

Appendix O
Outcomes Approach Logic Model

Program Rationale: Persons affected by cancer experience psychosocial distress



Note. Adopted from W. K. Kellogg Foundation (2004b, p. 54).

Input/Activities: Describes the activities conducted in the program. May include products, services, and infrastructure.

Outputs: Refers to the direct results produced by a program activity. Usually quantified in terms of size and/or scope of the services delivered or products produced.

Outcomes: Refers to short-term and long-term outcomes expected as a result of each activity implemented. May include individual changes in attitude, behavior, knowledge, skills, status, or level of functioning.

Impacts: Refers to the results expected 7–10 years after an activity has been implemented. Reflects the impact activities and subsequent results have on an organizational, community, or systems level. May include improved program conditions, expanded services, or changes in policy and procedures. (W. K. Kellogg Foundation, 2004b, p. 8)

Appendix P

Patient Support Services Patient Satisfaction Survey

We are interested in your feedback about our services. Please take a moment to complete this survey and return it to any reception desk or suggestion box. Thank you!

Are you a patient receiving treatment or a friend/family member? Patient
 Friend or family

Have you heard about the services available through the Patient Support Services Department? (counseling, social work, nutrition, support groups, etc.) *Please check one:*

- I am well informed
 I have some limited knowledge and know where to go if I need to
 I could use more information
 I have never heard about Patient Support

Gender: Male Female

Age: 18–25 26–34 35–44
 45–54 55–64 65–74 75+

Marital Status: Single Married or Domestic Partner
 Separated Divorced Widowed

Race/Ethnicity: Caucasian/White Hispanic/Latino
 African American/Black Asian/Pacific Islander
 American Indian/Alaska Native Other _____

What year did you start treatment at Providence Regional Cancer Partnership? _____

What type of cancer is being treated? *Please select all that apply:*

- | | | |
|---|---|--|
| <input type="checkbox"/> Aids-related Cancer | <input type="checkbox"/> Gestational | <input type="checkbox"/> Non-Hodgkin's |
| <input type="checkbox"/> Bladder Cancer | <input type="checkbox"/> Trophoblastic Cancer | <input type="checkbox"/> Lymphoma |
| <input type="checkbox"/> Bone Cancer | <input type="checkbox"/> Head and Neck Cancer | <input type="checkbox"/> Ovarian Cancer |
| <input type="checkbox"/> Brain Tumor | <input type="checkbox"/> Hodgkin's Lymphoma | <input type="checkbox"/> Pancreatic Cancer |
| <input type="checkbox"/> Breast Cancer | <input type="checkbox"/> Kidney Cancer | <input type="checkbox"/> Prostate Cancer |
| <input type="checkbox"/> Cervical Cancer | <input type="checkbox"/> Leukemia | <input type="checkbox"/> Skin Cancer |
| <input type="checkbox"/> Colorectal Cancer | <input type="checkbox"/> Liver Cancer | <input type="checkbox"/> Soft Tissue Sarcoma |
| <input type="checkbox"/> Endometrial Cancer | <input type="checkbox"/> Lung Cancer | <input type="checkbox"/> Uterine Cancer |
| <input type="checkbox"/> Esophageal Cancer | <input type="checkbox"/> Malignant Mesothelioma | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Gallbladder Cancer | <input type="checkbox"/> Melanoma | _____ |
| <input type="checkbox"/> Gastrointestinal Tumor | <input type="checkbox"/> Multiple Myeloma | _____ |

Stage of cancer: 0 I II III IV Unknown N/A

What treatment(s) have been received during the past 12 months? Select all that apply:

- | | |
|--|---|
| <input type="checkbox"/> Biopsy | <input type="checkbox"/> Palliative Care |
| <input type="checkbox"/> Hormone Treatment | <input type="checkbox"/> Hospice |
| <input type="checkbox"/> Radiation | <input type="checkbox"/> Clinical Research Trial |
| <input type="checkbox"/> Surgery | <input type="checkbox"/> Calmare Pain Therapy Treatment |
| <input type="checkbox"/> Chemotherapy | <input type="checkbox"/> Observation Only |
| <input type="checkbox"/> Other _____ | |

Have you used Patient Support Services at any point during treatment at Providence Regional Cancer Partnership? Please check one: Yes No

If so, which services have you used? Please check all that apply:

- emotional support during treatment (infusion, radiation, hospitalization)
- counseling with a PSS staff member (psychologist, social worker, intern)
- attending a support group: *which group(s)?* _____
- social work, resources, or financial assistance
- other _____

How likely are you to use or continue using Patient Support Services during your treatment at Providence Regional Cancer Partnership?

- Very Likely Somewhat Likely Maybe Somewhat Unlikely Very Unlikely

How satisfied have you been with the *quality* of services provided by Patient Support?

- Satisfied Somewhat Satisfied Neutral Somewhat Dissatisfied Dissatisfied

How satisfied have you been the *variety* of services provided by Patient Support?

- Satisfied Somewhat Satisfied Neutral Somewhat Dissatisfied Dissatisfied

How satisfied have you been with Patient Support Services staff access and responsiveness?

- Satisfied Somewhat Satisfied Neutral Somewhat Dissatisfied Dissatisfied

Do you consider Patient Support Services a valuable part of your cancer treatment at Providence Regional Cancer Partnership?

- Strongly Agree Agree Neutral Disagree Strongly Disagree

How likely are you to recommend Patient Support Services to other patients or family members?

- Very Likely Somewhat Likely Maybe Somewhat Unlikely Very Unlikely

In your experience, which Patient Support Services have been most helpful?

Please select one:

- Emotional support provided in the office or during treatment
- Support group opportunities
- Access to resources and financial support
- Other: _____

What else could Patient Support Services do to improve services?

Appendix Q

Patient Support Services Staff Satisfaction Survey

Number of years employed at PRCP:

< 1 1–2 3–4 5–6 8–9

Position: MD ACP RN MA

Other Clinical Staff Support Staff Administration

1. How familiar are you with the services offered by Patient Support?

5 4 3 2 1

Very Somewhat Not At All

2. How often do you refer patients or family members to Patient Support Services?

5 4 3 2 1

Very Often Sometimes Not At All

3. In what types of situations do you typically refer patients to PSS? *Please select all that apply:*

- Not applicable:** I don't refer patients in my position
- When a patient appears **upset or distraught**
- When a patient receives **upsetting news**
- When a **family member** has concerns or needs support
- When a patient has **difficulty understanding** diagnosis, prognosis, or treatment options
- When a patient appears **cognitively impaired or has difficulty comprehending** information
- When a patient's **health begins to decline**
- When a patient has **complex medical and/or psychosocial needs**
- When a patient appears **at risk of self-harm or injury** (i.e., intoxication, suicidality, domestic violence, vulnerable adult abuse)
- When a patient has **upset staff or other patients**
- When a patient has **financial concerns**
- When a patient has **transportation** concerns
- When a patient would benefit from a **nutrition consultation**
- When a patient would benefit from **additional time or attention** from staff
- Other: _____

4. What PSS resources do you usually recommend to patients? *Please select all that apply:*

- | | |
|--|---|
| <input type="checkbox"/> Financial/resources | <input type="checkbox"/> Support groups |
| <input type="checkbox"/> Counseling | <input type="checkbox"/> Social Work |
| <input type="checkbox"/> Cognitive testing | <input type="checkbox"/> Cancer Resource Center |
| <input type="checkbox"/> Nutrition | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> Other: _____ | |

5. Do you consider Patient Support Services a valuable part of PRCP's cancer treatment program?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5 | 4 | 3 | 2 | 1 |
| Very Much | | Somewhat | | Not Really |

6. Do you think Patient Support Services positively affects treatment outcomes for patients?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5 | 4 | 3 | 2 | 1 |
| Very Much | | Somewhat | | Not Really |

7. Research suggests several benefits when psychosocial services are offered along side cancer treatment. In your opinion, what outcomes might be likely to happen, in part because a patient has participated in Patient Support Services? *Please select all that apply:*

- Reduced risk of developing more severe emotional distress or disorders
- Improved ability to cope with expected distress throughout cancer treatment
- Improved overall health and level of functioning
- Improved satisfaction with the services available for cancer care
- Increased treatment compliance and follow up care
- Reduced workload for treatment providers or support staff
- Lower use of unnecessary medical or emergency services
- Reduced financial costs of our larger medical system

8. What do you think the Patient Support Services team does particularly well? *Please select all that apply:*

- Assesses psychosocial needs
- Facilitates support groups
- Provides emotional support to patients and family members
- Provides crisis intervention or urgent risk assessment

- Helps manage or triage patients with high acuity or psychosocial distress
- Other _____

9. What can Patient Support Services do to improve its services? *Please select all that apply:*

- Increase staff access during business hours
- Improve staff response time for urgent needs
- Offer support groups more frequently
- Offer more support service options
- Generate revenue or funding opportunities for the cancer center
- Offer publicity or marketing within our community to recruit patients
- Nothing! Keep doing what you're doing!
- I'm not sure
- Other: _____

If you would be willing to be contacted for a brief, informal interview to say more about your experience utilizing Patient Support Services, please provide your name for follow up:

Appendix R

Providence Regional Cancer Partnership Executive Summary

EXECUTIVE SUMMARY

PROGRAM EVALUATION OF PSYCHOSOCIAL SUPPORT SERVICES AT PROVIDENCE REGIONAL CANCER PARTNERSHIP- MAY 2016

NICOLA B. MUCCI, MA, LMHC

EVALUATION PURPOSE AND EVALUATION QUESTIONS

The purpose of this program evaluation was to better understand (a) how patients utilize Patient Support Services and (b) what patients and staff value about program services. This evaluation sought to provide an overview of program services as they are currently utilized and to offer informed program recommendations based on identified areas of satisfaction and dissatisfaction.

EVALUATION DESIGN AND METHODS

UTILIZATION OF SERVICES

- EHR audits: 300 single-use and multiuse participants; 100 group users
- Inclusion criteria: PSS participation July 2014–June 2015
- Data collected: Patient demographics (age, gender, insurance), diagnostic information (cancer origin, stage), treatment modalities (surgery, chemotherapy, radiation), PSS services (CRC, NT, FA, OV, INF, SG, family services)
- Utilization of services was compared among four sets of data: 1) all new cancer cases at PRCP, 2) single-use participants, 3) multiuse participants, and 4) group participants

SATISFACTION OF SERVICES

- STAFF SURVEY: Survey Monkey, forced-choice Likert scale
 - Inclusion criteria: Direct/indirect patient interaction
 - Response rate: 41 of 110 staff invited (37%)
- PATIENT SURVEY: Paper copies, forced-choice Likert scale
 - Inclusion criteria: Patients available during INF or SG July–October 2015 (n = 150); mailed to patients who attended new patient OV July–October 2014 (n = 440)
 - Response rate: 152 of 590 surveys distributed (26%)

EVALUATION FINDINGS PROGRAM STRENGTHS

UTILIZATION OF SERVICES

In general, utilization of services data appears to align with the mission of PSS

- While this evaluation is not an exhaustive analysis of utilization of services, it did demonstrate that more than 17.3% of all new patients at PRCP interacted with PSS beyond DA; services provided by one 0.8 MSW, 2 FT interns
- Participation in program services was highly reflective of patients' needs and presumed financial resources. Medicaid patients were more likely to participate in nearly all program services, despite comprising only 16% of participants and 7.5% of all new cancer cases. Medicare patients were more likely to request follow up on DAs, while commercial users were twice as likely to participate in SGs
- Advanced cancer patients used services more frequently and diversely. Stage IV patients represented 19.7% of all new cancer cases at PRCP, but represented 53% of multiuse participants

PATIENT PERSPECTIVE

- Eighty-two percent of patients are informed of program services
- Greatest program strength is emotional support
- High satisfaction of quality and variety of program services
- High satisfaction of staff access and responsiveness
- Psychosocial services perceived as having high value as part of cancer treatment
- Likelihood of using services or referring others to program services highly dependent upon prior use of services

STAFF PERSPECTIVE

- Sixty-eight percent of staff report familiarity of program services
- Highly regarded as being valuable and having positive effects on patient outcomes
- All program services recommended with high consistency
- Greatest program strength is emotional support
- Most perceived benefits of PSS: Increased ability to cope with distress, reduction in severe emotional disorders, higher satisfaction with cancer care treatment, increased treatment compliance, and increased overall health and functioning

PROGRAM LIMITATIONS AND RECOMMENDATIONS

Proposed recommendations are offered with input from PSS staff and other stakeholders

UTILIZATION OF SERVICES

- Women comprised 56% of all new cancer cases, but represented 68% of all program participants
- Breast cancer patients were superiorly overrepresented among all program participants and across all program services. Despite high national prevalence rates, male reproductive cancer patients were underrepresented across all new cancer cases as well as program services

PROPOSED RECOMMENDATIONS

- **Diversity of services (gender):** Market program services for men with cancer: Men represent 44% of all new cancer cases, but only 32% of program participants (15% group users and 36% of multiuse participants)
- **Diversity of services (cancer):** Based on projected prevalence rates of common cancer diagnoses reported by NCI, focus recruiting a more diverse group of patients to participate in program services
 - Program services should aim to target commonly diagnosed cancers that are similarly represented among all new cancer cases at PRCP. According to the NCI, the most commonly diagnosed cancers include bladder, breast, colorectal, endometrial, kidney, leukemia, lung, melanoma, non-Hodgkin lymphoma, pancreatic, prostate, and thyroid cancer
- **Support groups:** While SGs tend to be a well known aspect of cancer support services and have the potential to reach a large and diverse group of people, it is worth further evaluating how SGs are currently utilized at PRCP
 - Evaluate use of staff resources compared to attendance numbers, diversity of participants, and the ability to reach a large and broad audience
 - Evaluate how many SGs are needed to meet the emotional needs of patients and caregivers. Can current SGs be consolidated to reach a higher volume of patients (i.e., all men or all women with cancer) vs specialized SGs (i.e., women with breast cancer)? What is the advantage of offering open vs. closed groups that require registration or are held for a limited time (i.e., eight weeks) vs. ongoing?

- Evaluate what attracts the most attendees to SGs. For example, should funds be allocated to inviting guest speakers?

EDUCATION AND OUTREACH

IDENTIFIED CONCERNS

- Staff education and encouragement to use services; limited emphasis on “integrative services”
- Patient education and outreach
- Advertisement of program services

PROPOSED RECOMMENDATIONS

- **Staff education:** Only 37% of staff refer to PSS “often” and 39% refer “sometimes”
 - Create a quarterly PSS newsletter that includes staff biographies and specialties, patient narratives describing frequent scenarios or illustrating program resources and utilization of services. Distribute the newsletter via email and place hard copies in the staff lounge
 - Have a PSS representative attend quarterly all staff service meetings; have a PSS representative attend PRCP cancer conferences
 - During NEO job training, have new staff shadow a PSS staff member
- **Patient education and outreach:** Once a month, set up a “meet and greet” table in INF to distribute program information, answer questions, and increase staff visibility
 - Consider placing a support staff person in the first floor reception area to help direct patients and increase visibility of first floor services
- **Marketing and advertising:** Advertise PSS services in prominent locations such as INF and nursing stations; create quick fact sheets with PSS contact information, program services, and commonly requested resources (i.e., COPES, SSDI, transportation)
 - Consider investing in television monitors that can be mounted in common areas such as the waiting room. Screensavers can advertise program services, PSS biographies and contact information along with other PRCP information. Update the phone message to advertise PSS services while callers are on hold
 - Monitor the accuracy of current marketing materials and update information frequently (i.e., printed brochures, website information)

SERVICES AND ACCESS

IDENTIFIED CONCERNS

- Transportation services
- Transitioning onto hospice care
- Support for family members and caregivers (endorsed by patients + staff)

PROPOSED RECOMMENDATIONS

- **Transportation:** Provide handouts that advertise available transportation services and eligibility. Evaluate whether dissatisfaction reflects problems with transportation services and eligibility, or a deficit in how PRCP uses services.
 - Consider allocating PAF towards alternate transportation options (i.e., ferry tickets, bus fare) and additional gas cards
- **Hospice care:** Evaluate how and when referrals are made to hospice to better understand concerns and areas for improvement
- **Family services:** There is already a high inclusion of family involvement in services occurring naturally (17% single-use, 42% multiuse, 37% group). Market services for family members and caregivers more explicitly; create a brochure that markets services toward caregivers and include a list of outside resources available for caregivers

STAFFING

IDENTIFIED CONCERNS

- Training and education of PSS staff; inconsistency providing care (patient criticism)
- Staffing access—availability, visibility, and lack of full-time staffing (staff criticism)
- Response time on urgent needs—difficulty reaching staff and less than desirable response time on calls, pages, and DAs; ability to triage patients with high acuity ranked low as a department strength

PROPOSED RECOMMENDATIONS

- **Staff training and consistency:** Create a standard training program with learning modules on department needs for interns. Create procedural flow charts that illustrate level of patient care, available resources, and program services (i.e., COPEs, SSDI, PAF)
- **Staff access:** Create one centralized phone number to contact all PSS staff
 - FT staffing: Evaluate the ratio of full-time PSS staff to patients compared to other cancer treatment programs to determine if PRCP staffing is similar and/or sufficient
 - Evaluate the sustainability of the internship program. What is the long-term sustainability of PSS services based on current staffing conditions?
 - Visibility concerns may also be addressed via improvements made to staff education, patient outreach, and program marketing (as indicated above)
- **Response time:** Evaluate QA measures to assess timely follow up on urgent referrals and DA response time

ACRONYMS & ABBREVIATIONS

COPEs	Community Options Program Entry System (WA Medicaid program)
CRC	Cancer Resource Center
DA	Distress Assessment
EHR	Electronic health record
FA	Financial support (i.e., Patient Assistance Fund, SSDI applications)
INF	Infusion
MSW	Master of social work
NCI	National Cancer Institute
NEO	New Employee Orientation
NT	Nutrition
OV	Office visit
PAF	Patient Assistance Fund
PSS	Patient Support Services
QA	Quality assurance
SG	Support group
SSDI	Social Security Disability Insurance program

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- Appendix O. Outcomes Approach Logic Model



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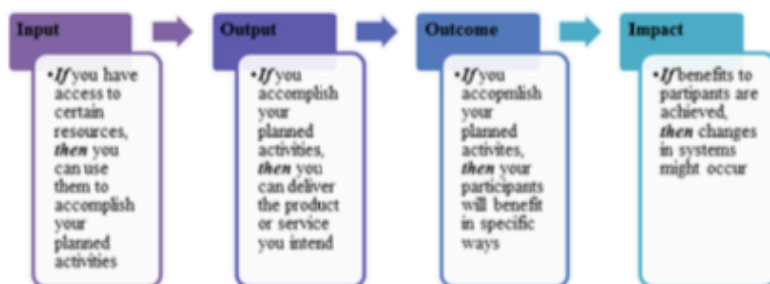
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