The Association of Health Literacy and Self-Efficacy to Cancer Chemotherapy Self-Management Behaviours and Health Service Utilization

By

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy

Institute of Health Policy, Management and Evaluation
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Abstract

Background

Increasing demands on Canada’s healthcare system require patients to take on more active roles in their health [1]. Effective self-management has been linked to improved health outcomes; and there is evidence that effective behaviours are linked to health literacy, however, this link has had minimal testing in the cancer context [2, 3]. Firmly establishing this link is important because those aged 65 years and older comprise the majority of the users of the cancer care system, and these individuals are most at risk for inadequate health literacy [4]. As such, the cancer care system may require increased self-management by patients least able to do so and, in doing so, fail to provide adequate care and incur substantial cost [5-7].

Objectives

To examine the association between health literacy and cancer chemotherapy self-management behaviours (CSMB) and health service utilization (HSU) and test the hypothesized relationship between self-efficacy and these outcomes.
Design
Cross-sectional survey.

Methods
Participants completed a questionnaire package with socio-demographic information and validated measures of health literacy, cancer coping self-efficacy, symptom severity, symptom interference, CSMB score, and HSU. Multivariate modeling using hierarchical linear regression was used to examine the association of health literacy to CSMB health services utilization.

Results
Education and language spoken at home explained a significant amount of variance (22.5%) in health literacy score. Health literacy was not significantly associated with any of the dependent variables in multivariate analysis. The analyses conducted to explore the association of self-efficacy to CSMB score and HSU showed that self-efficacy contributed to explaining variation in CSMB score but did not contribute significantly to explaining HSU.

Conclusion
This study provides new knowledge that advances understanding of the association of health literacy and self-efficacy on CSMBs and HSU in the context of cancer care.
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Chapter 1: Introduction

Increasing demands on Canada’s healthcare system will require patients to take on more active roles in their health [1]. Effective self-management has been linked to improved health outcomes; and there is evidence that effective behaviours are linked to health literacy, however, this link has had very little testing in the cancer context [2, 3]. Health literacy -- defined as, “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” [8]– is an important predictor of successful self-management in chronic diseases including diabetes, HIV and asthma [9]. Inadequate health literacy is associated with decreased patient engagement [10-13] which leads to worse self-management and, ultimately, poor health outcomes and preventable healthcare resource use [14] including emergency department use [15-19] and hospitalization [16, 17, 20]. Health literacy is a strong predictor of health status including morbidities associated with non-cancer chronic conditions including, for example, asthma [21], and worse physical and mental health [22]. Increasingly cancer is becoming viewed as a chronic disease; its treatment has also resulted in increasing demands on the healthcare system [23]. This study focuses on the role of health literacy in cancer self-management.

In Canada, an estimated 202,400 new cases of cancer occurred in 2016 and 78,800 cancer deaths were expected in the same time frame [24]. The incidence of cancer in Canada is rising and approximately 2 out of 5 Canadians will develop cancer in their lifetime [24]. The majority of these individuals are 65 and older; and this is the age group at greatest risk for inadequate health literacy [25, 26]. Minimal research has examined the role of health literacy on cancer self-management behaviours and subsequent healthcare utilization, and there has been little activity within the Canadian healthcare system to support individuals affected by cancer in learning effective self-management strategies [27].
In contrast, in diabetes and other chronic diseases, self-management strategies have been developed to mitigate the effects of inadequate health literacy, including the development of appropriate curricula to train patients and clinicians [26, 28]. These interventions have led to measureable improvements in clinical outcomes [29]. As such, self-management interventions designed for patients with inadequate health literacy can lead to significant cost savings to the healthcare system and improve patient quality of life [30, 31]. An important, unanswered question is whether similar strategies will be effective in cancer and what factors are associated with self-management behaviours. However, first there is a need to understand the contribution of health literacy to cancer self-management behaviours.

This gap in the empirical literature regarding the impact of health literacy during cancer treatment and afterward may be due to the emerging classification of cancer as a chronic disease based on increasing cancer survival leading to more people living with sequela of their treatments [23, 32, 33]. In addition, there is great need for self-management during the acute phase of cancer treatment [34]. Several prominent, international reports have advocated for the development and deployment of self-management strategies in chronic disease [33, 35-37]. However, cancer has only very recently been included on this agenda [23, 32] and, as such, there has been very little research on the predictors of cancer self-management strategies that successfully decrease health service utilization. Indeed, the cancer system lags behind other chronic diseases on self-management care [38, 39].

Evidence from other chronic diseases suggests that inadequate health literacy interferes with cancer self-management behaviours. First, inadequate health literacy leads to increased health service utilization in a broad range of settings [15-17, 20, 40-42]. Also, in other chronic diseases, health literacy is linked to effective performance of health behaviours that are similar to those required for self-management in cancer. These include: the interpretation of medication and nutrition labels [43-46]; adherence to and management of medications [47-52]; as well as having the confidence to perform needed behaviours (in other words, ‘self-efficacy’) [53, 54] and being activated to perform them [22, 40, 55-59]. However, cancer self-management has a unique set of demands and supports that distinguish it from self-management of other chronic diseases [23, 32]. Unlike most self-management that is focused on the post-treatment phase of healthcare,
cancer self-management behaviours have a significant role in the acute phase of cancer care [60]. Cancer patients and caregivers must process large volumes of information to aid in decision-making processes, adhere to complex treatment regimens, coordinate their care with multiple healthcare professionals, manage symptoms of cancer and its treatment and manage the emotional sequela of a cancer diagnosis [61-65]. Lack of self-management support in the cancer system leaves patients vulnerable to their disease and may explain the high rates of distress [66] and use of emergency departments during cancer treatment in Ontario [67, 68]. As such it is important to investigate the role of inadequate health literacy specifically in the cancer setting. Identification of the factors associated with cancer patients’ ability to self-manage their disease would enable the optimization of strategies to mitigate adverse effects [33, 69-73].

Better informed patients are better equipped to collaborate with healthcare providers to take an active role in their care and, as such, these patients have better health outcomes [2]. Informed patients decrease the demand for costly health services including treatment for advanced disease and emergency department use, while experiencing better health and quality of life [26, 32].

1.1 Cancer Self-Management Behaviours

There is a significant self-management role for cancer patients both in terms of the acute and chronic phases of their disease [74, 75]. The treatment phase is the acute phase of cancer care and during this phase, symptom management constitutes an important set of patient self-management behaviours [34]. This study is focused on the treatment phase. Unrelieved symptoms can: interfere with the patients quality of life and their ability to perform life roles [76]; are the cause of interrupted treatment, and can negatively influence its effectiveness [77]. They can also lead to serious medical problems that can be severe enough to necessitate admission to the emergency department or hospitalization [77] thereby adding substantially to the cost of treatment, disrupting the treatment plan and patient and family life [77]. The optimal management of symptoms and side effects requires a collaboration between healthcare providers and patients in which healthcare providers teach patients the requisite knowledge and skills needed to self-manage, and patients develop the ability to judge how and when to use them [10]. To do this effectively, patients require skills that are related to health literacy including the
use of written information, as well as skills that are related to self-efficacy, frequent self-assessments, and communication with healthcare providers [14, 28, 77, 78].

This is especially true of chemotherapy treatment when it is delivered in the ambulatory (outpatient) setting [23, 79]. Patients need to be able to identify symptoms early and take measures to prevent them or to contact their healthcare team before these problems are exacerbated [74, 75, 79]. Chemotherapy is a highly toxic cancer treatment that is associated with serious adverse effects if not managed properly [80]. Traditional chemotherapeutic agents act by killing cells that divide rapidly, which is one of the main properties of cancer cells. Subsequently, chemotherapy also harms non-cancer cells that divide rapidly under normal circumstances, e.g.: cells in the bone marrow, digestive tract, and hair follicles. This results in the most common side effects of chemotherapy: myelosuppression (decreased production of blood cells, and thus, immunosuppression), mucositis (inflammation of the lining of the digestive tract), and alopecia (hair loss) [81]. Patients with compromised immune systems are highly susceptible to life-threatening complications of chemotherapy [80]. Also, those with mucositis can suffer malnutrition and dehydration [80].

1.2 Health Behaviour Theories and Patient Activation in Managing Disease

A number of theories of health behaviour underline the central role of patients in the treatment and management of chronic disease. These theories explore the question ‘what makes a patient able to effectively self-manage illness?’ and propose that, in addition to health literacy, self-efficacy is an important predictor of behaviour change [56, 82, 83].

Self-efficacy is included as a predictor of self-management in Ajzen’s theory of planned behaviour and Bandura’s social cognitive theory [84, 85]. Both of these theories posit that self-efficacy is associated with an individual’s intention to act based, on their prior knowledge and experience of the requisite behaviour.

According to Bandura’s social cognitive theory, expectations such as motivation and performance determine behavioural reactions. He divides expectations into two distinct types: self-efficacy and outcome expectancy [86]. Bandura defines self-efficacy as ‘the conviction that one can successfully execute the behaviour required to produce the outcome’, and outcome expectancy is defined as ‘an individual’s estimation that a given
behaviour will lead to certain outcomes’ [86]. Bandura asserts that self-efficacy is the more important precondition for behavioural change (such as self-management behaviours), since it determines the initiation of coping behaviour.

Ajzen’s theory of planned behaviour (TPB) extends Bandura’s theory by further exploring the link between beliefs and behaviour [87]. TPB has been used to explain a wide range of health behaviours including the use of health services [84]. TPB posits that an individual’s behaviour is guided by their attitude toward the behaviours as well as subjective norms and the extent to which an individual believes they can control their behaviour [87]. This concept of perceived behavioural control originates from Bandura’s concept of self-efficacy [85].

Bandura’s self-efficacy theory was used to form the basis of the highly successful Chronic Disease Self-Management Program, conceptualized by Kate Lorig at Stanford University [88]. According to Lorig, perceived self-efficacy to self-manage is a patient’s confidence that they can accomplish a particular goal and as such, it is an important predictor of their ability to self-manage. Without this confidence, patients are less likely to participate in problem solving and decision-making in the context of their own health. Lorig has shown that under some circumstances, self-efficacy can mediate the effect of other health behaviour variables on self-management outcomes [89].

Inadequate health literacy is a potential barrier to self-efficacy [26]. For example, a prerequisite to having the confidence to perform the appropriate health behaviour is understanding what the necessary behaviour entails [26]. Since health literacy includes a focus on knowledge, individuals with inadequate health literacy may not have the knowledge they need to understand the necessary behaviour. There is some evidence, however, that high self-efficacy may compensate for inadequate health literacy [41, 52, 90-92]. However, no studies have explored the relationship between self-efficacy and health literacy in a cancer treatment context.

Self-efficacy and self-management behaviours of patients undergoing chemotherapy is important because inadequate self-management can have serious consequences for the patient, as well as generating high costs for the healthcare system through use of emergency departments and hospitalization [5, 93]. As a result of chemotherapy, physical
and psychological problems that surface during treatment and can persist as chronic problems well after cancer treatment has concluded [81, 93, 94].

Ambulatory chemotherapy treatment is an ideal setting for studying the factors that are associated with cancer treatment self-management behaviours. Chemotherapy self-management behaviours are established and are measurable with a validated instrument [79].

1.3 Research Problem Statement

The relationship between health literacy and cancer health behaviours and outcomes is not well understood. There is a significant gap in the literature regarding the association of health literacy on cancer self-management behaviours and health service utilization during treatment. The small number of studies of health literacy and cancer only examine the relationship between health literacy and the utilization of preventative cancer care behaviours [95, 96].

Self-management programs have improved the care of patients with other chronic diseases [89, 97]. They have significantly improved health outcomes while at the same time greatly reduced the costs of treating these patients [89]. Understanding whether inadequate health literacy is associated with cancer chemotherapy self-management behaviours as it is in other chronic diseases, and on health services utilization, this research stands to lay an important foundation for further work in this area. In particular, little is known about how inadequate health literacy effects cancer health behaviours, cancer self-management behaviours and health service utilization. This study provides initial data to advocate for system-wide changes to models of care provision and inform the development of self-management programs and materials for patients with inadequate health literacy in the cancer setting.

In summary, this work may contribute to a better understanding of the factors that are important to the enactment of self-management behaviours in cancer chemotherapy. It may contribute to strategies to better engage and educate patients as well as provide information that can aid in the development of interventions. It may also influence future models of care delivery that take into account important patient characteristics (e.g., those that are associated with inadequate health literacy) which may ultimately improve
efficiencies in health service delivery to optimize care and cost, and to improve the quality of life of individuals affected by cancer and other chronic diseases.

1.3 a) Study Purpose
The purpose of this cross-sectional study was to describe the levels of health literacy in cancer patients receiving chemotherapy and examine relationships between health literacy, socio-demographic variables, and self-efficacy on chemotherapy self-management behaviours and health care utilization.

1.4 Definition of Terms

1.4 a) Health Literacy
Health literacy is defined as “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” [8]. It includes a set of skills necessary for people to function effectively in the healthcare system and act appropriately on health information. These skills include the ability to interpret documents, read and write prose (functional literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy) [26].

1.4 b) Self-Management
Self-management, in the context of chronic disease, refers to a set of behaviours that patients must perform to manage their disease and overall health [78]. It is an active partnership between healthcare providers and patients to combine professional expertise with patient experiential knowledge [98]. Self-management is well-defined within the diabetes and arthritis literature it: “involves (the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment” [99].

1.4 c) Self-Efficacy
Self-efficacy may have significant effects on cancer self-management behaviours. Self-efficacy – a patient’s confidence in their ability to perform health behaviours – is associated with self-management and health outcomes [78]. Cancer coping self-efficacy is the specific type of self-efficacy that was measured in the research. It measures
behaviours that occur in the course of dealing with a cancer diagnosis, treatment and survivorship transitions [100]. As a specific type of health-related self-efficacy, cancer coping self-efficacy focuses on behaviours that are considered important for managing cancer including emotional, intellectual and physical behaviours. These include: the maintenance of daily activities; coping with treatment related side-effects; seeking and understanding medical information; and accessing support [101].

1.4 d) Health Service Utilization

Health service utilization refers to the level of use of available health care services over time. Health service utilization includes the use of hospital (e.g. emergency department use, hospitalization), community, and healthcare provider resources [102].

The next Chapter includes a section ‘Background on Key Concepts’ that includes some necessary background information derived from the general literature on the predictors and key concepts used in this dissertation. This background adds further precision to their definitions and clarifies some possible misconceptions about the terms. The section that follows, ‘Health literacy and Chronic Disease Self-Management’, describes the results of a formal, broad scoping review that was conducted to examine the empirical evidence for a relationship between health literacy and self-management outcomes in chronic disease. This review was done as a precursor to the review on cancer self-management behaviours because an initial informal review suggested almost no literature existed in this area. Note that the empirical support for including self-efficacy as an independent variable in this research was derived from this formal review.
Chapter 2: Literature Review

Initially, a broad scoping review of the literature was conducted to understand the relationship between health literacy and socio-demographic factors on self-management behaviours in non-cancer chronic conditions and to identify applicability of these behaviours to self-management in cancer populations. This broad scoping review was followed by a focused scoping review to explore what is known about the role of health literacy and other factors in cancer self-management behaviours and specifically during the acute active treatment phase of cancer.

The first section of this Chapter provides background to the conceptualization of terms: health literacy, self-management, cancer self-management and health literacy and chronic disease self-management. In the second section, results of the broad scoping review of the literature on health literacy and chronic disease self-management behaviours are summarized followed by the results of the focused scoping review of the literature on health literacy and cancer self-management behaviours.

2.1 Background on Key Concepts

2.1 a) Conceptualizations of Health Literacy

The concept of health literacy is evolving in the literature, and many conceptualizations of health literacy encompass more than just the ability to read and write. Several health literacy scholars call for a more expansive definition and much work is being undertaken to develop it as well as to develop measurement instruments [103-108].

Nutbeam and colleagues contend that a definition of health literacy that only takes into account the ability to read and write (functional literacy) in the context of health is too narrow [109-111]. Nutbeam asserts that this definition misses the deeper purpose of literacy for people; that is should not be regarded as a measure of reading and writing skills, but more in terms of what it is that literacy enables individuals to accomplish [109]. As such, health literacy is comprised of three parts: 1. Basic/functional literacy—sufficient basic skills in reading and writing to be able to function effectively in everyday situations; 2. Communicative/interactive literacy—more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of
communication, and to apply new information to changing circumstances; 3. Critical literacy—more advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations [109]. With this understanding, health literacy is defined as, “an outcome of health education and communication activities, it represents the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health” [109]. Nutbeam suggests that a definition of health literacy such as this means that progress is not dependent on cognitive development alone but takes into account individual exposure to health information/communication as well as other individual level skills and experiences [109]. Sorenson and colleagues developed a measure of health literacy based on this conceptualization, the European Health Literacy Survey Questionnaire (HLS-EU-Q) [111].

Zarcadoolas argues that health literacy comprises four different types of literacy including: 1) functional literacy, 2) scientific literacy, 3) civic literacy and 4) cultural literacy [108]. For example, an individuals’ health literacy level is informed by the scientific knowledge they possess about their specific health need (scientific literacy), their ability to access services and navigate the healthcare that they need (civic literacy), and their perception of the importance of that need at a specified time in their life (cultural literacy). Although this definition of health literacy greatly expands the definition by the Institute of Medicine [8], there is currently no way to empirically measure Zarcadoola’s conceptualization of health literacy.

Only recently, some researchers have begun to advocate for an expansion of health literacy skills to go beyond reading to include skills such as speaking and listening [112, 113]. At the same time, other researchers are suggesting that there is a need for context specific measures of health literacy. For example, Diviani and Dumenci have recently worked to validate measures of cancer literacy [114, 115]. Their research suggests that the cancer knowledge and skills required of laypeople is sufficiently complex to warrant separate conceptualization. Since the work of Diviani and Dumenci was under way at the
time that the research proposal for this dissertation was under development, there use was not considered for this research.

Health literacy researchers have also recommended an even more expansive definition of health literacy that takes into account the health literacy of health systems, healthcare provider training and communication skills, and the health literacy of patients [116]. A few questionnaires have been developed that endeavour to measure this more expansive definition [111, 117].

Although the more comprehensive definitions and measures for health literacy are compelling, for the purpose of this study, a measure of health literacy that accounts for functional literacy was used. This decision was made due to the fact that measures of functional health literacy, REALM [118], TOFHLA [119], Newest Vital Sign [120], have been used in a vast number of comparable health literacy studies to date. Since this study is among the first in cancer self-management, utilizing one of these measures allows more direct comparability between studies.

In general, an individual’s health literacy level is conceived of as being at one of three levels: low, moderate or high. For example, the scoring rubric in the widely used health literacy instrument the Test of Functional Health Literacy in Adults (TOFHLA) uses three categories that align with low, moderate and high based on an individual’s total score, inadequate, marginal, and adequate. Health literacy levels are referenced using the TOFHLA categories throughout this dissertation.

In addition, health literacy level, when defined by functional literacy, is thought to be relatively static because of the difficulty and time required to improve an individual’s literacy level [121]. For example, improving a health literacy score would require that an individual improve their ability to read and write which is time consuming and unlikely to occur in a healthcare context. As such, an individual’s health literacy level is thought to remain constant, as such a single measurement suffices in short-term studies.

2.1 b) Conceptualizations of Self-Management

Self-management can be a beneficial strategy for coping with increased demands on the healthcare system and in response to advances in treatment [12]. Self-management refers
to a program of care that promotes a patient’s ability to manage the symptoms and the consequences of living with a chronic condition. Examples of patient self-management behaviours include: exercise; management of symptoms; management of stress; use of community supports; and communication with clinicians [10, 78].

The National Health Service in the United Kingdom has established self-management programs (e.g., The Expert Patient Program) as part of standard care for patients with chronic diseases. Evaluation of these programs has demonstrated that they provide significant savings to the public healthcare system [11]. In particular, the benefit of self-management programs in chronic disease for both short and long-term conditions has been firmly established for the management of diabetes, asthma, epilepsy, arthritis, and multiple sclerosis [78]. Self-management programs have also been shown to improve: knowledge and understanding of disease and treatment, treatment compliance, symptom management, as well as quality of life and ability to cope [122, 123]. Self-management behaviours are also associated with decreased health services utilization [78].

Although a significant number of studies have established the benefits of self-management programs it should be noted that not all self-management programs accomplish their intended goals [124]. It would be interesting to explore the influences of effective self-management programs and to determine whether there is a difference in the quality of the interventions from the perspective of health literacy. For example, do the interventions that do not demonstrate benefit follow best practices for health literate design. The Agency for Health Research and Quality published a systematic review to explore qualities of interventions that follow health literacy practices [26]. They found that interventions were only effective for individuals with inadequate health literacy when they were developed using health literate best practices including plain language.

The terms “self-care” is at times used interchangeably with self-management and there is currently a lack of consensus about the meaning and usage of these terms in the research literature [125]. According to a thematic analysis conducted by Jones et al to distinguish self-care from self-management, there is significant overlap between the concepts but they differ in the networks involved, the imperative for action, and the goals to be achieved [125].
In general, self-care is used in the acute care context and self-management in the chronic disease setting. In self-care, the network involved can be the patient alone or the patient with community, family and clinicians. In self-management, the network involved is focused and includes the patient, possibly family, and their healthcare provider. The main outcomes of self-care include prevention and maintenance of health while the main outcomes for self-management are coping and controlling. Exemplars of self-management behaviours according to Jones et al include: active participation by the patient in symptom management and engaging in a wide range of generic and condition specific tasks. Conversely, self-care actions include a wide range of strategies aimed at health promotion and secondary and tertiary prevention. It is broadly focused on the prevention of disease, accidents, limitations of illness, and restoration of health, recovery from minor ailments and after recovery from hospital.

Patient education, another term that is used interchangeably with self-management, generally refers to a didactic approach to teaching rather than a collaborative approach between patient and healthcare providers.

In this dissertation, for clarity and consistency, Jones’ definition of self-management is used and it refers to the set of behaviours that patients that are undergoing chemotherapy must perform to reduce symptoms and to optimize their quality of life.

2.1 c) Cancer Self-Management

Cancer occurs on a continuum with six major phases: prevention, screening, diagnosis, treatment, survivorship, and end of life care [126]. Each phase in the continuum places multiple demands on the healthcare system and as a result, models of care are moving to shared models in which increasingly more responsibility is placed on the patient [127].

In cancer, self-management is important at each of the six phases in the continuum of care. For example, in the prevention phase, important self-management behaviours can include practicing sun safety, quitting smoking, and maintaining a healthy diet. In the screening phase, effective self-management involves participating in regular screening for early detection of cancers (i.e., mammography, Papanicolaou testing, and colorectal cancer screening) [23]. Post-diagnosis and during treatment, symptom management becomes important as unrelieved symptoms can interfere with patient quality of life and
their ability to perform life roles [23]. Inadequate symptom management can also be the cause of interrupted treatment and can thus influence its effectiveness [128]. Unrelieved symptoms can also lead to increased use of emergency departments and hospitalization that can add substantially to the cost of treatment, disrupt the treatment plan, and also disrupt patient and family life [77]. In the post-treatment phase, patients must take a significant role in managing side effects of cancer and its treatment; monitoring for late and long-term effects; and communicating with their family physicians, oncology specialists and other healthcare providers [127]. The self-management behaviours that are important for cancer patients are numerous, complex, and time-varying; as such, cancer self-management places a substantial demand on the patient and their families [129].

2.1 d) Health Literacy and Self-Management

The literature suggests that there are many factors that contribute to a lack of effective self-management behaviours. These include provider training, and various patient-level and health system level factors [26, 130, 131]. Health literacy, as a patient-level factor, may play a significant role in the cancer patients’ ability to effectively self-manage their disease [123]. Managing chronic conditions requires that patients are able to understand and access health information, make changes to their lifestyles, make informed decisions, and understand how to access care when they need it [132]. This is a significant challenge because, according to the Canadian Public Health Association, over 60% of adults in Canada have inadequate health literacy skills [26, 133]. This number is even greater when we consider patients over 65 years of age, who constitute the majority of new cancer patients [25]: 88% of Canadians older than 65 have inadequate health literacy [4, 25]. Inadequate health literacy is likely even more problematic for those that require complicated care and self-management, like cancer patients. As such, inadequate health literacy could pose significant challenges for the cancer treatment system.

2.2 Literature Review

2.2 a) Health Literacy and Chronic Disease Self-Management

The results of the review are summarized by outcome and these summaries also include discussion on their applicability to cancer self-management behaviours.
Literature Search Strategy

This scoping review followed the guidelines of Arksey and O’Malley [134]. It was conducted to examine and summarize the evidence for a relationship between health literacy and self-management behaviours and health outcomes in chronic disease in preparation for a more focused review on cancer self-management behaviours. A comprehensive search of OVID Medline was conducted in consultation with a health information specialist. The search was limited to articles in English, published between 1990-November 3, 2013. The date 1990 was chosen because prior to this, the concept of health literacy was not well known [135]. It was not updated for this dissertation research because it was meant as background to the formal literature review on health literacy and cancer self-management included below. Of note is that a limitation of this literature review is that it was restricted to articles that were accessible through OVID Medline only. A more comprehensive search strategy that included additional databases may have yielded greater results. Inclusion criteria were: 1) study populations of adult patients and caregivers with chronic disease, 2) outcomes related to self-management behaviours and other health outcomes, 3) health literacy was measured using a validated instrument, and 4) studies had to be published. The types of studies included in the review were cross-sectional, longitudinal, or controlled trials (observational or experimental). Only quantitative studies were included as the purpose of the review was to examine the empirical evidence of associations between health literacy and various self-management behaviours and outcomes.

A Microsoft Excel workbook was used to manage all records. Data abstraction was performed by the author and the following information was collected for each record: author(s), publication year, study location, study population, study objective(s), study design, measure of health literacy, outcome variables, and important results. Studies that met inclusion criteria were summarized using a qualitative narrative synthesis approach as per Arksey and O’Malley guidelines [134].

Summary of Results

The search terms used were ‘health literacy’ and ‘self manag*’ and yielded a return of 216 records. The search term ‘chronic disease’ was added to the initial search and the
yield was reduced to 32 records. Thirty-two records were deemed to be too limited and as
such, all 216 records were examined. First, record titles were reviewed to eliminate studies that did not meet inclusion criteria. When it was not possible to determine exclusion by title, abstracts were reviewed. Following title and abstract review, and removing duplicate records, 77 articles remained that met inclusion/exclusion criteria. Several articles were literature reviews and because all of the studies included within those reviews were already included among the 77 articles, the literature reviews were removed. Subsequent hand-searches of the reference lists of the remaining articles resulted in the addition of 7 further articles. Review of full articles led to the identification of some that did not meet the inclusion/exclusion criteria. Once these were removed, 66 articles remained.
Among the sixty-six studies, there were twelve different outcomes measured that could be broadly divided into three categories: 1) behaviours directly relevant to chemotherapy self-management (device use, medication adherence, interpretation of prescription labels, and daily self-management roles), 2) direct medical outcomes (health service utilization, health status, and mortality) and 3) decision-making skills (use of comparative information, disease knowledge and beliefs, and satisfaction with health care). Ten different chronic diseases were represented: HIV, asthma, diabetes, cancer, heart failure, hypertension, chronic back pain, arthritis, renal disease, pulmonary obstructive disorder.
There were substantial methodological limitations with many of the studies. Most studies utilized cross-sectional designs and/or convenience samples that limited the generalizability of the findings and causality could not be established. Nonetheless, the effects of inadequate health literacy when they were detectable and confounders accounted for, were consistent: inadequate health literacy predicts unfavourable outcomes such as: poor disease knowledge and beliefs, poor medication adherence, inability to correctly interpret prescription labels, inability to use comparative information, poor health status and mortality. However, the only studies on health literacy in a cancer context considered use of preventative health services, and not treatment-related self-management behaviours.

The twelve different outcome variables examined in the sixty-six studies in this review included: medical device use (n=3) [136-138], disease knowledge and beliefs (n=12) [17, 41, 54, 56, 59, 91, 92, 96, 139-142], daily self-management (n=10) [28, 143-151], medication adherence and management (n=9) [47-52, 152-154], interpretation of medicine and nutrition labels (n=5) [43-46, 155], self-efficacy (n=6) [52, 57, 92, 146, 150, 152], patient activation (n=7) [22, 40, 55-59], health service utilization (n=20) [15-20, 41, 42, 53, 95, 96, 142, 156-163], use of comparative health information (n=2) [164, 165], health status (n=6) [16, 17, 21, 22, 156, 159], satisfaction (n=1) [40], and mortality (n=2) [41, 42]. More detail about each study included in this review can be found in the Appendix.

**Health Literacy and Medical Device Use**

Medical devices are used in cancer care including external infusion pumps that are used to deliver fluids (i.e. nutrients and medications such as chemotherapy) into a patient’s body in a controlled manner [166]. Infusion pumps are used in both the clinical and ambulatory setting. A number of problems have been reported with infusion pumps including inadequate interface design making it difficult for patients to use, alarm errors, and software problems [166]. These problems can lead to serious medical problems such as over or under infusion, missed treatment, and delayed therapy [166]. To mitigate these problems, patients need to know what to expect from the infusion pump including the duration of time that it should take for the medication to be delivered. This knowledge could help patients identify potential problems with the infusion pump and get help.
Patients also need to know how to use the pump in terms of changing a battery or showering with the device. Although devices in cancer care is important, no studies were found that examined device use in the cancer setting.

The three studies that examined the relationship between health literacy and device use were focused on the use of asthma inhalers and taken together demonstrate mixed findings [136-138]. There were methodological limitations for these studies that included: insufficient sample sizes to power the analysis [136, 137], one of them did not report an effect size [136] and used a non-validated measure of the outcome variable asthma knowledge [136] which could result in information bias where it is not known whether the outcome was measured appropriately. Both studies did not adjust for potential confounders in the analysis although several potential confounders are known [136, 137]. For example, insurance status is an important potential confounder because it may influence whether patients seek medical care or advice. This is especially important in studies that are set in contexts without universal health insurance, such as the United States and each of these three studies were conducted in the United States.

Two of these three studies also examined whether health literacy levels were associated the extent to which participant learned, about inhaler techniques, through an asthma inhaler self-management training intervention [136, 137]. One of these studies found that regardless of health literacy level, there were improvements in inhaler technique post intervention however, as indicated above, this study had several limitations that bring the findings into question. The other intervention study found no significant relationship between health literacy level and inhaler technique pre or post intervention although it also had many of the same methodological limitations of the aforementioned study [137].

Taken together, evidence from only one of the three studies is sufficient to demonstrate a relationship between health literacy level and asthma inhaler technique score [138]. This study found that inadequate health literacy predicted poor asthma inhaler technique scores (coefficient -1.3, 95% CI: -1.7 to -0.9; p<0.001). However, the study population was sampled by convenience and thus the results are not generalizable. In addition, the study design was cross-sectional which means that causality cannot be determined. Further experimental research studies using probabilistic sampling methods are needed to firmly establish the link between health literacy and asthma inhaler technique. This work
suggests that future research investigating the relationship between infusion pump use and health literacy in the cancer setting could be important.

**Health Literacy and Disease Knowledge and Beliefs**

Knowledge and beliefs about disease can influence patient behaviours in terms of identifying potential problems and communicating these to healthcare providers [26]. In cancer care, inaccurate knowledge and beliefs about cancer and its treatment could affect delays in diagnoses and, possibly, the efficacy of treatment [167]. Twelve studies examined the relationship between health literacy and knowledge and beliefs about disease, screening practices, and therapies [17, 41, 54, 56, 59, 91, 92, 96, 139-142]. Of these twelve studies, eleven show evidence of an association between health literacy and disease knowledge and these are described below. Five of the twelve studies examined knowledge and beliefs about cancer screening [41, 92, 96, 142, 158] and none examined cancer knowledge or beliefs outside of the screening context.

Four studies examined the relationship between knowledge of colorectal cancer screening practices and health literacy and yielded mixed results [41, 92, 96, 142]. Three studies found that inadequate health literacy was significantly associated with less knowledge about colorectal cancer screening and with more reported barriers to completing FOBT screening in adjusted multivariate analysis [41, 92, 96]. However, these three studies had insufficient sample sizes for the statistical tests employed [41, 92, 96] and one of them did not report effect size [41]. The study that found no relationship between knowledge of colorectal cancer screening and health literacy utilized an adequate sample size [142].

One study examined the relationship between knowledge of mammography and health literacy level among Latinas [158]. The study found that in adjusted analysis, health literacy is only weakly associated with knowledge of mammography (OR, 1.11; 95%CI: 1.04-1.19). This study was cross-sectional and had an insufficient sample size to power the statistical analysis employed.

The remaining seven studies considered other chronic diseases. Four studies examined asthma knowledge or beliefs among asthmatics [17, 138, 139, 168]. Each of these studies showed health literacy to be a strong predictor of asthma knowledge or belief score. For
example, one study found that parents of asthmatic children with inadequate health literacy had less asthma knowledge than parents in the higher literacy group. Parents with inadequate health literacy scored a mean of 14/20 on the asthma knowledge scale while parents with adequate health literacy scored a mean of 16/20 (P<.001) [17]. A cohort study showed that in adjusted multivariate analysis, incorporating data from baseline and 12 months, that health literacy was associated with asthma belief score – those with inadequate or marginal health literacy were more likely to believe they would not always have asthma (OR: 1.84, 95% CI: 1.2-2.82) or that a doctor could cure their asthma (OR: 2.22, 95% CI: 1.29-3.82) however there was no significance found between health literacy and the belief that no symptoms means no asthma [139].

Only one study examined the relationship between knowledge of chronic disease and health literacy level [2]. In adjusted analysis health literacy was independently associated with chronic disease knowledge: the regression coefficient (r) ranged from (r=0.13; p<0.001) in hypertension knowledge to (r=0.28; p<0.001) in asthma knowledge. This study used probabilistic sampling methods that support the generalizability of its findings, but it was cross-sectional and as such, causality could not be determined. In addition, the inclusion of an age cut-off for the sample (65 years of age and older) was not justified and may introduce selection bias and could further limit the generalizability of the findings. Also, the dependent variable was measured using a non-validated instrument and as such may introduce information bias to the study findings.

A study by Torres et al examined the relationship between knowledge of hormone therapy and health literacy levels among menopausal women [91]. The study found a positive relationship between health literacy and knowledge in bivariate analysis (r=.64; p<.01). However, this study used a convenience sample, was cross-sectional, and did not employ multivariate adjusted analysis when examining the relationship between knowledge of hormone therapy and health literacy level.

A study by Wallace et al examined the effects of a diabetes self-management intervention on participant knowledge of diabetes self-management strategies and diabetes related health outcomes [54]. This study found that the intervention yielded similar improvements in diabetes self-management knowledge for participants with inadequate and marginal health literacy levels post intervention; adequate health literacy
group: mean pre-intervention score= 60.83, post= 67.77, mean change = +6.94; marginal/inadequate health literacy group: pre-intervention score= 51.77, post= 56.98, mean change = +5.21. Although this study employed a prospective cohort design, it only used bivariate analysis, as such as, was unable to detect confounding effects or other interactions among the independent variables.

Several of these studies had methodological limitations that diminish the strength of the findings. However, eleven of the twelve studies produced evidence to suggest that knowledge in the context of health is associated with health literacy level. This includes asthma knowledge, knowledge and beliefs about colorectal cancer and mammography screening, knowledge of chronic disease, knowledge of hormone therapy and diabetes self-management knowledge. Further research that uses appropriate sample sizes, validated measures of all independent and dependent variables, and employs appropriate multivariate analyses is needed to strengthen the evidence of an association between health literacy and knowledge of cancer screening as well as knowledge of chronic diseases.

**Health Literacy and Daily Self-Management**

Daily self-management is important at various times throughout the cancer care trajectory as it is for many diseases [74, 75]. These self-management activities include, monitoring symptoms, coping with nutrition challenges, and pain management [23, 77, 169]. Despite the importance of these behaviours, none of the twelve studies that examined the relationship between health literacy and daily self-management skills were within the cancer setting [28, 143-151].

Two studies examined the relationship between daily asthma self-management behaviours and health literacy level [147, 150]. One study found a statistically significant association between less successful daily asthma self-management and inadequate aural health literacy (OR:4.65, 95% CI: 1.11-18.86). However, this study had a very small sample size and the results suggest that the sample size (n=68) was inadequate to power the analysis [147]. The second study that used a probabilistic sample of parents/guardians of asthmatic children, did not report findings on parent health literacy level and child level of daily asthma self-management although this was stated as one of the outcomes of interest in the study [150]. Six studies examined the association
between daily diabetes self-management behaviours and health literacy [28, 144-146, 148, 151]. Two of these studies found that health literacy was positively associated with diabetes self-management behaviours [148, 151] while the other four found no significant associations [28, 144-146]. The four studies that found no significant associations had inadequate sample sizes for the statistical tests employed [28, 144-146] and one of them did not report which potential confounders were included in adjusted analysis [144].

The two studies that reported significance were both National studies (N=14,257; N=1318) that utilized cross-sectional designs with large, probabilistic samples [148, 151]. One found that after adjustment, the three measure of health literacy, problems learning (OR 1.4, CI 1.1-1.7), needing help reading (OR 1.3, CI 1.1-1.6), and lack of confidence with forms (OR 1.3, CI 1.1-1.6) were independently associated with significant hypoglycemia [148]. In the other, health literacy was significantly associated with self-graded assessment of diabetes self-care ($R^2 = 0.231$) [151]. Both of these studies made appropriate adjustments to account for potential confounders in the analysis. The other study examined the relationship between daily pain self-management and health literacy level [143]. In bivariate analysis, patients with chronic back pain had a significantly lower score in one of the eight domains of the measure of health literacy (HeLMS) with a moderate effect size - "Patient attitudes toward their health" (mean difference 95% CI, 0.11-0.82, $d=0.65$). The sample size was small (n=80) and as such, there is insufficient evidence to support this relationship.

A randomized controlled trial to examine the impact of an arthritis self-management intervention by health literacy level and race found that in the intervention group (telephone) compared with health education, pain management improved more among participants with inadequate health literacy than those with adequate health literacy however the result was not statistically significant [149].

Four of the twelve studies found evidence of an association between health literacy and daily self-management behaviours [143, 147, 148, 151]. These show that health literacy level may be associated with daily self-management practices in asthma [147], diabetes [148, 151], and chronic back pain [143].
Health Literacy and Medication Adherence and Management

Medication adherence and management in cancer care is important during treatment and after [170]. For example, adherence to antiemetic regimens, prescribed as prophylaxis for chemotherapy induced nausea and vomiting, can be a deciding factor of whether a patient is able to complete their course of chemotherapy [171]. Another example can be seen in the use of the hormone therapy Tamoxifen. Tamoxifen is used in the treatment and prevention of breast cancer and there is evidence that women who do not adhere to their prescribed dose have an increased risk of death compared those that do [172]. Despite an extensive literature on the importance of medication adherence and management in cancer, none of the nine studies in this review were focused on cancer. Nine studies examined the relationship between health literacy and medication adherence and management [47-52, 152-154] and of these, seven found evidence of an association between these variables [47-52, 153].

Six studies examined HIV medication adherence [49, 51, 52, 152-154]. Four of the six studies found inadequate health literacy to be a significant, independent predictor of HIV medication non-adherence [49, 51, 52, 153]. For example, one study (n=318) found in adjusted multivariate analysis, that inadequate health literacy was a significant independent predictor of two-day treatment adherence (OR 3.9; 95% CI: 1.1-13.4). Also, persons with inadequate health literacy were more likely to miss treatment doses because of confusion, depression, and a desire to cleanse their body than persons with adequate health literacy [49]. Each of these four studies employed cross-sectional designs with convenience sampling and thus causality cannot be established and the generalizability of these findings is limited.

A study by Apter et al examined the association between asthma medication management and health literacy level [47]. This prospective cohort study found that higher health literacy was associated with better adherence to asthma medication (β=8.00, 95% CI, -0.77 to 16.77; p=.07).

Another study examined the association between adherence to anti-coagulation medications and health literacy level [48]. The study found that poor anticoagulation control (measured by variability of the international normalized ratio - INR) was higher among patients with inadequate health literacy, for example, the INR variability was 32%
higher in patients at the lowest health literacy level as compared with patients at the highest health literacy level. In multivariate analysis, only the potential confounder “age” was included.

The final study in this review examined whether coronary heart disease medication management was associated with health literacy level [50]. This study found that health literacy is a strong predictor of patient inability to identify medications. However, this study may have introduced information bias to the results by using only part of a validated instrument to measure the outcome variable. The study team elected to do this because all of the participants scored high on one portion of the instrument.

Taken together, there is some evidence of an association between medication adherence and health literacy level. Although none of these studies examined medication adherence or management in the context of cancer, it possible that the findings could translate to the cancer setting.

**Health Literacy and Interpretation of Prescription and Nutrition Labels**

Taking medication as prescribed is critical to optimizing treatments. As such, patient ability to interpret prescription labels is important. This is true for cancer patients who may have a number of different medications to take at home during treatment including medication to treat their cancer as well as medications to reduce side effects [79, 173]. In addition, cancer medication dosing schedules can be complex which leaves a wide margin for misunderstanding [174]. Only five studies were found that examined the relationship between health literacy and interpretation of prescription [43, 44, 46, 155] and nutrition labels [45] and none of these were in the cancer setting. Each of the studies that examined the association between understanding prescription labels and health literacy however, found that inadequate and marginal health literacy levels were significant predictors of dosing error or lack of knowledge about dosing [43, 44, 46, 155]. One study found, in a multivariate analysis, that inadequate and marginal health literacy were significant predictors of misunderstanding prescription labels after controlling for age, sex, and education (inadequate health literacy: AOR 3.18, 95% CI=1.60-6.32; marginal health literacy: AOR 2.33, 95% CI=1.31-4.14; AUROC =0.66; Hosmer-Lemeshow $\chi^2 =0.50$). Despite these findings, none of these studies used a
validated instrument to measure the dependent variable and as such, may have introduced information bias to study findings.

The study that examined the association between understanding nutrition labels and health literacy level found in adjusted multivariate analysis that inadequate health literacy was significantly associated with poorer performance on the nutrition label survey [45] (the nutrition label survey is a validated instrument used to measure patient comprehension of nutrition labels). Unfortunately, the authors did not report effect size and as such, the strength of the evidence is unclear [45].

Taken together, there is some evidence of a relationship between lower levels of health literacy and misunderstanding prescription and nutrition labels. However more research is needed to support findings. In addition, this work should be extended to the cancer context where patients are often prescribed multiple drugs, with complicated dosing instructions, some of which can have serious adverse effects if taken incorrectly [174].

**Health Literacy and Self-Efficacy**

According to Bandura, self-efficacy is a proximal or direct predictor of behaviour change [85]. Evidence from a systematic review that examined applications of Bandura’s theory of self-efficacy in oncology suggests that there is a relationship between self-efficacy and cancer prevention behaviours as well as with patient ability to adapt to having cancer [175]. As such, self-efficacy may contribute to the enactment of chemotherapy self-management behaviours but no studies were identified that examined this specific relationship. This review found six studies that examined the relationship between health literacy and various types of self-efficacy (i.e. medication-taking self-efficacy, diabetes self-care self-efficacy) [52, 57, 92, 146, 150, 152] and among these, only one study was in the cancer context [92].

Three of these studies found evidence of a relationship between health literacy and self-efficacy [52, 57, 92, 150]. For example, health literacy was positively associated with self-efficacy for diabetes self-care in multivariate analysis while controlling for patient and clinical characteristics ($r=0.251$, $p=0.003$) however, the effect size was small [57]. Another study found that high health literacy was associated with high self-efficacy for participating in colorectal cancer screening with a medium effect size ($\beta=0.061$, 95% CI,
One of these studies conducted mediation analysis and found that self-efficacy mediates the impact of inadequate health literacy on medication adherence (AOR 7.4, 95% CI, 2.7-12.5) [52].

One of the two studies that did not find evidence of a relationship between health literacy and self-efficacy utilized a sample size that was inadequate to power the analysis (n=50) [146]. The other study that did not find evidence of an association between health literacy and medication-taking self-efficacy among individuals with HIV although it had an adequate sample size for the analysis performed and utilized validated measures of all independent and dependent variables [152].

Taken together, this work demonstrates that different types of self-efficacy are positively correlated with health literacy across different contexts and that it is possible that other types of self-efficacy, including medication-taking self-efficacy, are not. It further shows that self-efficacy can mediate the effects of inadequate health literacy on medication adherence. As such, self-efficacy may mediate the effects inadequate health literacy on other self-management behaviours.

**Health Literacy and Patient Activation**

This review found seven studies that examined the relationship between health literacy and patient activation [22, 40, 55-59], however none of these were conducted within the cancer context.

Each of the seven studies found evidence of a positive relationship between adequate health literacy and higher levels of patient activation although some showed stronger evidence than others. For example, one study found that in their sample (n=527), patients with adequate health literacy were more activated (had higher patient activation scores) than their counterparts (P<.001) however, they did not report effect size [58]. Another study showed that in a probabilistic sample of 697 patients, a weak correlation and small effect size between health literacy and patient activation (r=0.11, p<0.01) [22].

Of these seven studies, only one of the studies included mediation analysis. This study examined the contribution of both health literacy and patient activation as predictors of comprehension to find that higher patient activation can help those with inadequate
health literacy compensate for lower skills [164]. Those with inadequate health literacy and high patient activation scored ten points higher on the comprehension measure than those with both inadequate health literacy and low patient activation.

**Health Literacy and Health Service Utilization**

Twenty studies examined the relationship between health literacy and health service utilization [15-20, 41, 42, 53, 95, 96, 142, 156-163]. The specific health service outcomes measured were: preventative health practices (i.e. cancer screening, vaccines) [95, 96, 142, 156, 158-160, 163], emergency department visits [15-17, 53, 161], hospitalizations [17, 19, 20, 41, 42], medical costs associated with emergency room use [18], and access to healthcare services [157, 162]. None of these studied health service utilization in the context of cancer treatment however, despite that known consequences of complications during chemotherapy include emergency department visits and hospitalizations [176].

All but four of these twenty studies found an association between inadequate health literacy and health service utilization [41, 53, 142, 161]. This was especially true among adults aged 65 and older which is corroborated in the health literacy literature [163]. All of the eight studies examining preventative services found that inadequate health literacy was associated with less use of preventative health services [95, 96, 142, 156, 158-160, 163]. For example, in a study that examined cervical cancer screening practices among Latina immigrants, compared to those with adequate and marginal health literacy, women with inadequate health literacy were significantly less likely to have ever had a Pap test (OR, 0.12; 95% CI, 0.04-0.37) or in the last three years (OR, 0.35; 95% CI, 0.18-0.68) and were significantly more likely to have had their last Pap test in a local public hospital (OR, 2.43; 95% CI, 1.18-4.97). When controlling for other factors, women with inadequate health literacy were 16.7 times less likely (adjusted OR, 0.06; 95% CI, 0.01-0.55) to have ever had a Pap test [95].

Each of the five studies that examined the relationship between health literacy and emergency department use found evidence of an association between health literacy level and emergency department use [15-17, 53, 161]. For example, a large prospective national study (N=3260) found that overall, the relative risk of having two or more visits to the emergency department was higher for those with marginal and inadequate health
literacy than those with adequate health literacy (adjusted OR, 1.44; 95% CI, 1.01-2.02) and (adjusted OR, 1.34; 95% CI, 1.00-1.79) respectively [15]. Another study conducted path analysis and found that health literacy had a direct and negative effect on emergency department use ($\beta$=−0.35) [16]. Each of these studies utilized adequate sample sizes for the analysis completed.

Four of five studies that examined the relationship between health literacy and hospitalization found a statistically significant association between them [17, 19, 20, 42]. For example, in a study that examined the association of parents’ health literacy levels on hospitalization of their children due to asthma exacerbation, children of parents with low literacy had greater incidence of hospitalizations (IRR 4.6; 1.8, 12) even after adjusting for asthma-related knowledge, disease severity, medication use, and other sociodemographic factors [17]. Another study examined the relationship between health literacy and 30-day post-discharge re-hospitalization. In adjusted multivariate Poisson regression analysis, the incidence rate ratio for individuals with inadequate health literacy compared with adequate health literacy was (IRR 1.46; 95% CI, 1.04-2.05) [20]. The one study that did not find evidence to support an association between health literacy and hospitalization was a retrospective cohort study (n=1494) that examined the relationship between health literacy and all-cause hospitalization among patients with heart failure [41]. It is possible that health literacy only affects hospitalization among specific patients in specific circumstances. Since none of these studies examined hospitalization in the cancer chemotherapy context, research to do so is warranted by the strength of the evidence articulated here.

One national study examined the relationship between costs incurred in emergency rooms among patients by health literacy level [18]. This study found that emergency room costs were significantly higher among those with inadequate health literacy even when insurance status and other potential confounders were accounted for [18].

Two studies examined the association between access to health care services and health literacy level [157, 162]. One of these studies was a large national study (N=2500) and found in adjusted multivariate analysis that older people with inadequate health literacy were twice as likely to have one or more of three indicators of poor access to healthcare than those with marginal or adequate health literacy [162]. The other study found that
patients with inadequate health literacy were less likely to be referred for transplant evaluation than those with adequate health literacy [157]. The sample size was very small for the study examined referrals for transplant evaluation and the statistical analyses employed were inappropriate given the size.

Taken together, there is strong evidence of an association between health service utilization and health literacy level but the strength of the association may vary by context. None of the studies included in this review examined the relationship between health literacy level and health service utilization in the context of cancer treatment and as such, research in this area is warranted.

**Health Literacy and Use of Comparative Information**

Patients undergoing cancer treatment often need to make decisions about treatment choices. Optimal decision-making in this circumstance requires using comparative health information. Comparative health information refers to comparative performance data on health resources including: providers, treatment plans, and hospitals [177].

Two studies examined the relationship between health literacy level and use of comparative health information [164, 165]. Both found evidence that compared with individuals with marginal and adequate health literacy, those with inadequate health literacy have less ability to use comparative health information. Both of these studies had adequate sample sizes for the analysis performed but were cross-sectional which cannot be used to establish causality and both sampled by convenience which limits the generalizability of the findings.

**Health Literacy and Health Status**

Health status is a commonly used clinical measure of well-being. Good health status is important in all chronic diseases, including cancer. Six studies examined the relationship between health literacy and health status [16, 17, 21, 22, 156, 159]. All of the studies concluded that health literacy predicts health status. The specific health statuses that were examined include asthma status [17, 21] and general health [16, 22, 156, 159]. For example, one study that examined the association of health literacy on general physical and mental health found in adjusted multivariate that inadequate health literacy was associated with worse physical health (b = 0.13, p=0.001) and depression (b=20.16,
Three of these studies were National in scope [21, 156, 159] and two employed cohort designs with probabilistic sampling methods [156, 159].

**Health Literacy and Satisfaction**

One cross-sectional study examined the relationship between health literacy and asthma patient satisfaction [40]. This study found that patients with inadequate health literacy were less satisfied with their asthma status as well as less satisfied with the quality of the medical care that they received (\( p \leq .005 \)) however an effect size was not reported [40]. Although this study was focused on asthma patient satisfaction, patient satisfaction has been a major concern in cancer care for several years and it continues to be an important indicator of quality care at Cancer Care Ontario [178].

**Health Literacy and Mortality**

Two studies examined the relationship between health literacy and mortality [41, 42]. Both studies found that inadequate health literacy was independently associated with higher mortality. One study only found this association for ambulatory patients with heart failure \( n=595, \) [42] while the other study, \( n=1494, \) examined all-cause mortality [41]. The study that examined all-cause mortality found that in multivariable Cox regression, inadequate health literacy was independently associated with higher mortality (unadjusted rate, 17.6% vs 6.3%; adjusted hazard ratio, 1.97; 95% CI, 1.3-2.97); \( p<.001\) [41].

**Summary of Limitations**

Several of the sixty-six studies had significant methodological limitations. The majority of the studies employed cross-sectional designs that cannot be used to establish causality (\( n=47 \)). Also, most of the studies sampled by convenience that limits the generalizability of findings (\( n=51 \)). Some studies introduced selection bias by excluding potential participants based on unjustified age cut-offs (\( n=7 \)). Furthermore, several studies had inadequate power for the statistical tests employed (\( n=22 \)) and a number did not report effect sizes (\( n=9 \)) that may suggest the presence of publication bias where effect size is not reported either because it was not large or statistically significant. The vast majority of the studies were conducted in the United States (\( n=64 \)) however adjustments for the potential confounder ‘insurance status’ were only made in thirteen of these studies.
Summary

In chronic disease, health literacy is associated not only with activities directly relevant to chemotherapy self-management (device use, medication adherence, interpretation or prescription labels, and daily self-management roles) but also direct medical outcomes (health service utilization, health status and mortality) and decision-making skills (use of comparative information, disease knowledge and beliefs, and satisfaction with health care). The evidence for these relationships varies, and the studies were often underpowered or have other methodological limitations, but the forty-five studies which were able to detect an effect (thirty-one of which are methodologically sound) all agree that inadequate health literacy has a negative impact on beneficial self-management outcomes. There were five studies that included measures of self-efficacy and were methodologically sound. These reported a positive relationship with health literacy and one showed that high self-efficacy mediates the effects of inadequate health literacy. Finally, with very few exceptions, even the methodologically sound studies used cross-sectional design, so causality could not be established and most studies used convenience samples, as such, findings are not generalizable.

2.2 b) Health Literacy and Cancer Self-Management Behaviours

A more focused scoping review of the literature was conducted to examine and summarize what is known about the association of health literacy on self-management behaviours and health service utilization in cancer setting. The literature review question addressed was, “What is known from the existing literature about the association of health literacy on self-management behaviours and health outcomes in cancer?”

The methodological framework articulated by Arksey and O’Malley was employed and the applicable procedures to scoping reviews outlined in both the PRISMA and the Cochrane review guidelines were followed [134, 179, 180]. Scoping reviews are used to summarize and disseminate research findings, the range of research in a particular field of study, as well to identify gaps in the current body of knowledge as well as to determine the value of undertaking a full systematic review [134]. The literature review research focus was refined using the PICOTS framework outlined in the Cochrane guidelines: **Population:** adult patients and caregivers of all races and ethnicities; **Intervention:** no requirement for an intervention; **Comparison:** health literacy or
numeracy levels; Outcomes: psychosocial outcomes (i.e., quality of life), clinical outcomes (i.e., chemotherapy symptom management, radiation symptom management) and health service utilization outcomes (i.e., ED use, hospitalization); Time: defined as being either cross-sectional or longitudinal studies (observational or experimental), with varying lengths of time for follow-up, and with no restrictions for when the studies or data collection activities were done. Setting: inpatient or outpatient settings in health care systems and institutions, various community-based settings, or homes will be included in the review.

**Literature Search Strategy**

A comprehensive search was conducted in consultation with two health science librarians. The following electronic databases were searched to identify relevant studies and search strategies were customized for each database: OVID Medline; EMBASE; Cumulative Index to Nursing and Allied Health Literature (CINAHL); PsycINFO and Education Resource Information Centre (ERIC). The search was limited to articles that are available in English and were published between 1990-January 2017 because valid instruments to measure health literacy were not developed or widely used until 1992 [181]. As per Arksey and O’Malley guidelines, once articles were identified that met the inclusion criteria reference lists for each study were reviewed to determine whether any relevant literature was missed in the electronic search strategy. Hand searching of key journals was also employed to identify any additional relevant studies as follows: Journal of Cancer Education; Patient Education and Counseling; Health Services Research and Policy.

**Search Terms**

The search for eligible studies included the following search terms: information literacy: health literacy, computer literacy; neoplasms: cancer*, tumor*, carcin*, neoplasm*, metastas*, oncolg*; self-management: self car*, selfcar*, self manag*, self monitor* (to see complete list of search terms, see Appendix IV).

**Data Abstraction and Management**

Endnote bibliographic software package was used to manage all references. Two reviewers performed data abstraction independently (JP and TP). Data was extracted
from articles and charted. The following information was collected for each study as per Arksey and O’Malley recommendations: author(s), year of publication, study location, study population, aims of the study, methodology, measure of health literacy, outcome variables, and important results.

Types of Studies

Cross-sectional or longitudinal studies (observational or experimental) were included. The studies had varying lengths of time for follow-up, and there were no restrictions for when the studies or data collection activities were done.

Inclusion

Studies included in this review were published in peer-reviewed journals. The study population consists of adult patients and caregivers of all races, ethnicities, and cultural groups. Use of an instrument to measure health literacy was required. Eligible study designs included: before-and-after studies; controlled trials; and observational studies: prospective and retrospective cohort studies, case control studies and cross-sectional studies. Relevant outcomes were abstracted from data presented in the papers.

Exclusion

Original research studies that provided sufficient detail regarding methods and results were included. In addition, studies not published in English were excluded.

**Method of Appraisal**

Procedures applicable to scoping reviews for study appraisal as outlined in the Cochrane guidelines were followed. Data abstraction and appraisal was performed independently by two reviewers (JP and TP) using a priori criteria to conduct study selection. An initial title scan was conducted and when relevance was difficult to glean from the title, the abstract was retrieved and reviewed. The full article of all articles that meet inclusion criteria was reviewed.

**Data Analysis**

Studies that meet inclusion criteria were summarized qualitatively and a narrative summary of the results reported as per the Arksey and O’Malley guidelines [134]. First, a basic numerical analysis of the studies included in the review was done. A Table was
produced to map the distribution of studies geographically, for different patient populations, and for the range in intervention types and outcomes. Secondly, the literature was organized thematically according to study design. A descriptive template was applied to each study to ensure that the same attention and questions were asked of each study to limit reviewer bias and create a transparent review process. The strength of evidence for an association of health literacy to self-management behaviours was determined based on a priori criteria that included whether the statistical tests employed were appropriate, for example, was the sample size adequate to power regression analysis. In addition, a flow diagram was created as per PRISMA guidelines to demonstrate the review process, how many studies were identified, screened, eligible and included in the review [180].

**Summary of Results**

The initial search of the databases yielded 2,414 articles. After removing duplicates and conducting title and abstract scans of these articles, the number of eligible articles was reduced to 44. Of the 44 full text articles reviewed, 17 studies meet the inclusion criteria by addressing the relationship of health literacy to various and self-management behaviours in cancer [92, 96, 182-196].
An inclusion criterion for this review was use of a psychometrically validated measure of health literacy. Eight different measures of health literacy were used: the Rapid Estimate of Adult Literacy in Medicine (REALM) (7 studies) [41, 96, 182, 186-188, 191, 196]; the Test of Functional Health Literacy in Adults - United Kingdom (UK TOFHLA) (1 study) [92]; Short Test of Functional Health Literacy Adults (S-TOFHLA) (5 studies) [182-184, 191, 195]; the Short Assessment of Health Literacy in Spanish Adults (SAHLSA) (2 studies) [182, 194]; the Measurement of Health Literacy in Europe – German Short Form (HLS-EU-Q16) (1 study) [193]; the Functional Communicative and Critical Health
Literacy Scale – Dutch (FCCHL) (1 study) [185]; and the Brief Health Literacy Screen (1 study) [192]. Two studies utilized more than one measure of Health Literacy [182, 183] and one study created a hybrid measure using the REALM and STOFHLA [191]. The health literacy levels used to compare study participants varied among studies, with either use of health literacy as a continuous measure or categorization of health literacy into two or three groups (i.e., inadequate, marginal, and adequate). Studies varied concerning whether the two lower or the two higher groups were combined.

Of the seventeen studies, fourteen were observational; of these, twelve used a cross-sectional design [41, 92, 96, 183, 185, 186, 188, 189, 192-195] and two were longitudinal cohort studies [182, 184]. Three studies employed experimental designs, one was quasi-experimental with 3-arms [187] and the other two were randomized controlled trials [191, 196].

Among the seventeen studies that met the inclusion criteria, there were 7 different categories of outcome variables examined: 1) daily self-management behaviours (n=2): radiation self-care [196], and medication adherence [191]; 2) health service utilization (n=6): mammography [187, 189], colorectal cancer screening [96, 194, 195], and chemotherapy [184]; 3) disease knowledge and beliefs (n=8): breast cancer information needs [193], breast cancer screening beliefs [182, 186], cancer worry [188], and colorectal cancer screening beliefs [41, 92, 96, 194]; 4) health status (n=3): complications post surgery [192], psychosocial measures (i.e., anxiety, depression) [183] and cancer stage at diagnosis [184]; 5) self-efficacy (n=3): colorectal cancer screening self-efficacy [41, 92], and general self-efficacy [183]; 6) decision-making skills (n=1): chemotherapy [184]; 7) satisfaction (n=1): online self-management education program [185]. Below, more specific quantitation is provided, followed by a summary of select studies.

**Health Literacy and Daily Self-Management**

Two studies explored the association between health literacy and daily self-management behaviours and the specific behaviours were, medication adherence and radiation self-care behaviours [191, 196]. Rust et al found that health literacy is associated with medication adherence (B = .582, 95% CI [28.42, 41.73], r = .29, t(46) = 2.07, p = .044,
two-tailed) with health literacy contributing 8.5% of the overall variance in medication adherence score [191]. However, there were significant methodological limitations with this study. First the sample size n= 48, is not sufficient to power regression analysis and second, the study team developed a measure of health literacy by combining questions from two validated measures of health literacy (REALM, S-TOFHLA). The unfortunate consequence of this was that the health literacy measure had very low internal consistency reliability (Cronbach Alpha .43) and as such, lowers the quality of the study.

The second study that explored the association between health literacy and daily self-management was another experimental study that sought to determine whether an education intervention for prostate cancer patients post radiation therapy would improve patient self-care of the side effects from treatment [196]. They sought to compare patient self-care behaviour scores based on health literacy level. This study found that men with inadequate health literacy in the usual care group had a significant decrease in self-care from pre to post-intervention, whereas men in every other group and health literacy level showed an improvement from pre to post intervention. The sample size (n=70) for the statistical analysis employed was insufficient and as such, the evidence of an effect of health literacy is weak.

**Health Service Utilization**

Six studies explored the association between health literacy and health service utilization [96, 184, 187, 189, 194, 195]. Two studies explored whether health literacy was associated with uptake of mammography [187, 189]. The study by Davis et al (n=1,181) showed statistically different levels of effectiveness between three arms of education interventions to promote mammography (P<0.0001). The study by Komenaka et al (n=1,664) found study participants with inadequate health literacy were less likely to get a mammogram than their adequate health literate counterparts (odds ratio [OR] 0.27, 95% confidence interval [CI] 0.19-0.37; P<.001). The strength of both studies was high and as such, there is strong evidence of an association between health literacy and uptake of mammography.

Three studies explored the association between health literacy and colorectal cancer screening [96, 194, 195]. The findings for an association are mixed – the study by Todd et al (n=103) found that participants who were current screeners had higher health
literacy scores (p=0.042) than their lower health literate counterparts [195]. A study by Miller et al (n=50) found no effect of health literacy on colorectal cancer screening [96] and a study by Shelton et al (n=400) found an association between health literacy and colorectal cancer screening adherence in bivariate analysis but the finding did hold true in regression analysis [194]. The evidence of an association between health literacy and colorectal screening is moderate.

The final study in this literature review focused on receipt of prescribed chemotherapy [184]. This study (n=347) found that having adequate health literacy increased the chances that patients with stage III/IV cancer received chemotherapy (odds ratio [OR] = 3.29, 95% [CI] 1.23, 8.80) but had no effect on cancer stage at diagnosis or vital status at last observation during post-enrollment follow-up. The evidence for an association between health literacy and receipt of prescribed chemotherapy is strong.

The results of the six studies together provide evidence for an association between health literacy and health service utilization in the context of cancer; however more adequately powered studies are needed.

**Health Literacy and Decision Making**

The Busch et al study that explored the association between health literacy and receipt of chemotherapy also explored whether health literacy level was associated with decision-making about chemotherapy [184]. They found that the differences were not statistically significant but participants with stage III/IV disease with adequate health literacy played a more prominent role in deciding whether to have chemotherapy than those with inadequate/marginal health literacy.

**Health Literacy and Self-Efficacy**

Three studies explored the association between health literacy and self-efficacy [41, 92, 183]. vonWagner et al (n= 96) found that inadequate health literacy was associated with less self-efficacy for colorectal cancer screening (b = .61, 95% CI, .009–.131). Peterson et al (n=99) also found no association between health literacy and self-efficacy for colorectal cancer screening [41]. Bezler et al (n=168) found no association between health literacy and general self-efficacy in a sample of bone marrow transplant patients [183]. Taken together, the strength of evidence for an association between health literacy
and self-efficacy for colorectal cancer screening is moderate.

**Health Literacy and Health Status**

Three studies explored the association between health literacy and health status [183, 184, 192]. A study by Scarpato et al (n=368) found that higher health literacy was associated with decreased odds of developing minor complications post surgery for radical cystectomy (OR= 0.90, 95% CI [0.83,0.97]) [183, 184, 192]. Busch explored with health literacy level was associated with cancer stage at diagnosis and found that across all stages, having adequate health literacy did not increase the odds of presenting with early-stage (I/II) disease compared with presenting with late-stage (III/IV) disease (OR=1.11, 95% CI [0.68, 1.80]). A study by Bezler at al (n=168) found association between health literacy level and various measures of psychosocial health (i.e., anxiety, depression). Taken together, there is strong evidence to support an association between health literacy and the development of minor complications post-operation however, further research to investigate this association in other surgical settings would be helpful.

**Health Literacy and Satisfaction**

A study by Cnossen et al (n=55) explored whether health literacy was associated with participant satisfaction with an online self-care education program supporting early rehabilitation of patients after total laryngectomy [185]. They found that satisfaction with the program was significantly associated with higher health literacy levels (p=.038). The strength of evidence of an association between health literacy and satisfaction is weak due to a small sample size and also because the cross-sectional design and the statistical analysis employed can show evidence of a relationship between these variables but nothing further.

**Health Literacy and Disease Knowledge and Beliefs**

Seven studies explored the association between health literacy and disease knowledge and beliefs [41, 92, 96, 182, 188, 193, 194].

Kelly et al (n=96) explored the relationship between health literacy and cancer worry and found no association [188].
Schmidt et al (n=1248) whether the information needs of breast cancer patients differed by health literacy level. They found that higher information needs on the following topics were associated with lower health literacy: follow-up care (adjusted OR = 0.297; 95% CI [0.163–0.542]), long-term side effects (adjusted OR = 0.20; 95% CI [0.105–0.408]) and inheritability (adjusted OR = 0.479; 95% CI [0.270–0.849]). Armin et al (n=71) found no significant association between breast self-exam knowledge and practices among women with different health literacy levels.

Miller (n=50) found that participants with inadequate health literacy were less likely than adequate health literacy patients to be able to name or describe any colorectal cancer screening test (50% vs. 96%, p < 0.01). In a multivariable model, participants with inadequate health literacy were 44% less likely to be knowledgeable of CRC screening (RR 0.56, p < 0.01) [96]. The sample size in this study was insufficient to power regression analysis and as such, the strength of these findings are limited. Another study (n= 99) that explored the association between health literacy and colorectal cancer screening knowledge found no association in adjusted analysis between health literacy colorectal cancer screening knowledge [41]. A study by Shelton et al (n=400) also found no association between health literacy and colorectal cancer screening knowledge [194].

A study by vonWagner et al explored whether health literacy level was associated with information seeking about colorectal cancer screening and they found in multivariate analysis that lower health literacy is associated with less information seeking (b = .079, 95% confidence interval, .001–.157) [92]. Taken together, the strength of an association between health literacy and colorectal cancer screening is weak however, and interestingly, it seems that there is an association between health literacy and information seeking.

The results of these eight studies together point to a need for further investigation. Schmidt found that participants with inadequate health literacy had higher information needs that their adequate health literate counterparts and vonWagner found an association between health literacy and information seeking behaviours which could imply that individuals with inadequate health literacy have great information needs because they are less likely to seek information, however, it could also follow then that
individuals with inadequate health literacy have less knowledge about disease and these findings have not been corroborated in the literature.

Summary of Limitations

There were substantial methodological limitations with some of the studies. Those free of these limitations utilized cross-sectional designs and/or convenience samples and as such, the generalizability of the findings from individual studies was limited and causality difficult to establish. Each of the three studies that utilized an experimental design sought to evaluate an educational intervention by comparing outcomes by intervention type and health literacy level [187, 191, 196]. The findings from these studies were mixed but lend support to the evidence that patient education can mitigate the effects of inadequate health literacy [26]. Furthermore, these studies demonstrate an association between health literacy and cancer self-management behaviours. For example, Davis et al found statistically different levels of effectiveness of intervention arm on mammography rates by health literacy level (P<0.0001) [187]. Wilson et al also found a statistically significant difference in post prostate cancer radiation therapy side-effect self-care behaviours overtime between the intervention groups when health literacy level was taken into account (F2, 63 = 3.55; p = 0.03) and this showed that men with inadequate health literacy in the usual care group had a significant decrease in self-care from pre to post-intervention, whereas men in every other group and health literacy level showed an improvement from pre to post intervention [196]. Rust’s study on the other hand, showed no effect of the intervention on either arm or by health literacy level but found that breast cancer survivors with adequate health literacy were associated with higher rates of adherence (B =.582, 95% CI [28.42, 41.73], r = .29, t(46) = 2.07, p = .044, two-tailed) and self-efficacy for appropriate medication use (B = .834, 95% CI [12.29, 30.50], r = .32, t(46) = 2.29, p = .027, two-tailed) [191]. Although two of these studies lend support to the benefit of patient education interventions on cancer self-management behaviours (use of cancer screening and radiation self-care), one of the studies had a very small sample size (n=70) for the statistical analysis employed and this brings its findings into question [196]. The study that showed an association between health literacy and medication adherence and medication adherence self-efficacy, also had a very small sample size (n=48) that was inadequate to power the analysis used. The authors noted that the study was a pilot in preparation for a randomized controlled trial [191].
Nonetheless, the results showed that inadequate health literacy is associated with some cancer self-management behaviours: less uptake of cancer screening behaviours [187, 189, 195]; less uptake of prescribed chemotherapy [184]; greater likelihood for post-operative complications [192]; higher information needs [193] and less information seeking behaviours [92].

**Summary**

This literature review shows that in cancer, health literacy is associated with important self-management behaviours. The implications of these associations for individuals with inadequate health literacy, as well as to the healthcare system are significant. For example, the implications of the findings that inadequate health literacy is associated with uptake of cancer screening behaviours can mean that individuals with inadequate health literacy are at a greater risk of cancer, and of presenting to the cancer care system at more advanced stages of disease. The finding of an association between health literacy and receipt of prescribed chemotherapy could have implications for patient outcomes and for mortality. In addition, the finding of an association between health literacy and greater risk of post-operative complications could point to worse outcomes for individuals with inadequate health literacy and more costly care including recidivism to the hospital. More research is needed to explore the associations between specific cancer self-management behaviours and health literacy to better understand the scope of the problem and to focus attention to these areas.
Health literacy researchers, Michael Paasche-Orlow and Michael Wolf, articulated a conceptual framework to explore the causal mechanisms that link health literacy with health [130]. They describe the systematic, interactional, and self-care mechanisms by which limited health literacy is most likely to contribute to poor health outcomes. The socio-demographic factors that determine health literacy level in the Paasche-Orlow and Wolf model were derived from the empirical literature [130]. There is strong agreement in this literature that each of these factors are predictors of health literacy level and this is corroborated by a recent systematic review conducted by the Agency for Healthcare Research and Quality on health literacy and outcomes [26]. The Paasche-Orlow and Wolf model proceeds to shows how health literacy can impact health outcomes at three points in the continuum of care. These factors are: Access and Use of Health Care, Provider-Patient Interactions, and Patient Self-Care [130]. At each of these three points of care, Paasche-Orlow and Wolf explore factors that could moderate or mediate the relationship between patient health literacy and outcomes (see Figure 1) [130]. These factors are: System factors (e.g., complexity, acute care orientation, tiered delivery system); Provider factors (e.g., communication skills, teaching ability, time, patient-centred care); Patient factors (e.g., navigation skills, self-efficacy, knowledge, motivation); and Extrinsic factors (e.g., support technologies, mass media, health education, resources) [130].
The relationship proposed by the Paasche-Orlow and Wolf model between health literacy and patient self-management informed the conceptual framework adapted for use in this study. Of note is that Paasche-Orlow and Wolf employ the term ‘self-care’ in their model however the meaning that they use is aligned with the conceptualization of ‘self-management’ used in this research. Although each of these points of care are important, for the purpose of this research, this study is centered on the Patient ‘Self-Care’ portion of the model with a focus on only the patient-level factors.

The Paasche-Orlow and Wolf model suggests important patient-level factors to consider within the Patient Self-Care domain. These are: motivation, self-efficacy, problem-solving, knowledge and skills [130]. In this research study, the Paasche-Orlow and Wolf model has been adapted to examine a specific outcome, chemotherapy self-management.
and as such, the patient-level factors included in the original model are replaced by factors that have been empirically and theoretically shown to predict similar self-management behaviours. Any patient-level factor identified by Paasche-Orlow and Wolf that could not be quantified with a validated instrument has been substituted in the adapted model with variables that can be. In this research, health literacy, and cancer coping self-efficacy are included as independent variables in the model, and chemotherapy self-management and health service utilization are the dependent variables (see Figure 4).

![Adapted Paasche-Orlow and Wolf Causal Model](image)

Key socio-demographic variables, (age, sex, education, income, country of birth and language spoken at home) are antecedent variables that have been empirically shown to predict health literacy levels [26, 130]. Possible confounding variables were identified through a review of the literature and these are: symptom severity and symptom interference [26].

In the adapted model, health literacy level is a predictor of the dependent variables chemotherapy self-management score and health service utilization score. According to the empirical literature, inadequate health literacy is directly associated with poor self-management behaviours [143, 147, 148, 151] and with greater utilization of health services including Emergency Department use and more hospitalization [15-17, 19, 20,
Accordingly, in the hypothesized model, inadequate health literacy scores will predict lower chemotherapy self-management scores and also greater utilization of health services (emergency department visits and hospitalization). Based on empirical literature and theory, self-efficacy, will have a direct effect on the dependent variables. Chemotherapy self-management has a direct relationship to health service utilization because poor self-management is associated with greater health service utilization. The disease variables, symptom severity and symptom interference, have a direct relationship with chemotherapy symptom management and in turn, health service utilization.
Chapter 4: Methods

4.1 Study Purpose

The purpose of this cross-sectional study was to describe the levels of health literacy in cancer patients receiving chemotherapy; and examine relationships between health literacy, socio-demographic variables, and self-efficacy on chemotherapy self-management behaviours and health care utilization. Four research questions were explored.

4.2 Research Questions and Hypotheses

Research Question 1: What is the distribution of Health Literacy scores in cancer patients receiving chemotherapy?

Hypothesis 1: Health Literacy scores will be clustered on the low end of the measure (inadequate health literacy).

Research Question 2: What are the associations between Health Literacy and socio-demographic variables, self-efficacy, symptom severity and symptom interference?

Hypothesis 2: Socio-demographic variables that are known to be associated with health literacy will also be correlated with health literacy in this sample, i.e., Health Literacy score, which is on a continuum from low to high, is significantly negatively correlated with older Age; Health Literacy score is positively correlated with Education and Income scores; Health Literacy score is significantly positively correlated with Country of Birth and Language Spoken at Home (in that, participants born in Canada and those that speak English at home would have higher Health Literacy scores).

Research Question 3: Is health literacy level associated with chemotherapy self-management behaviours independent of symptom severity, symptom interference and self-efficacy?

Hypothesis 3: Health literacy contributes independently and significantly to explaining the variation in Chemotherapy Self-Management score.
**Research Question 4:** Is health literacy level associated with health service utilization independent of symptom severity, symptom interference, self-efficacy and independent of chemotherapy self-management behaviours?

**Hypothesis 4:** Health literacy contributes independently and significantly to explaining the variation in Health Service Utilization scores.

### 4.3 Study Design

A cross-sectional design was used to identify health literacy levels and associations between cancer patients undergoing chemotherapy at one point in time. A cross-sectional design allows an examination of multiple outcomes that are important to this investigation [197]. In addition, a cross-sectional survey allows for quick and efficient data collection and because the association of health literacy to chemotherapy self-management behaviours has not been studied to date, a cross-sectional design is appropriate. In addition to producing results for this study, the results will inform the design of future studies in this area.

### 4.4 Study Setting

All adults, aged eighteen and older, diagnosed with cancer, in at least the second cycle of chemotherapy treatment in the ambulatory (outpatient) setting at the Princess Margaret Cancer Centre in Toronto during the period of recruitment (six months), were invited to participate in the study. The Princess Margaret Cancer Centre is the largest cancer hospital in Canada and treats over 12,000 individuals newly diagnosed with cancer each year.

### 4.5 Sampling Strategy and Recruitment

The study population consists of adults receiving chemotherapy for treatment of cancer in the ambulatory setting. Participants were in at least the second cycle of chemotherapy to allow sufficient manifestation of symptoms and side effects to require self-management [198]. Participants were recruited consecutively using convenience sampling during outpatient chemotherapy clinic appointments at the Princess Margaret Cancer Centre, Toronto, Ontario. Eligibility criteria were as follows:

**Inclusion Criteria**
Participants were at least eighteen years of age or older; undergoing chemotherapy treatment; in at least the second cycle of treatment; and could speak English.

Exclusion Criteria

Participants were excluded if they had limited English proficiency and/or physical impairments that would prevent survey completion (e.g. visual impairment).

4.5 a) Sample Size

Sample size was determined based on the regression equation with the maximum number of variables, the regression that was meant to assess moderation of health literacy by self-efficacy on health service utilization. This regression equation has six independent variables: health literacy, self-efficacy, chemotherapy self-management score, symptom severity, symptom interference, the interaction term between health literacy and self-efficacy. D = βAA + βBB + βEE + βFF + βGG + βABAB + error

Health Literacy (A), Self-Efficacy (B), Chemotherapy Self-Management Score (E), Symptom Severity (F), Symptom Interference (G), and the interaction term between Health Literacy and Self-Efficacy (AB). The dependent variable (D) represents health service utilization.

An *a priori* power calculation for hierarchical regression was conducted using G*Power* software to determine the appropriate sample size for this regression using an F-test with the significance level at 0.05, and the number of tested predictors at three (health literacy, and the interaction term), and total number of predictors at seven. The total sample size needed to achieve 95% power to detect the $f^2$ change of 0.15 is 153. Based on a 35% non-participation rate, 235 patients need to be recruited to meet this sample size.

Recruitment feasibility was based on average number of new breast, colorectal and head and neck cancer patients treated with chemotherapy/year for 2011 (534) and 2012 (530)[199]. These cancer diagnoses were selected because they represent the largest number of patients treated with chemotherapy at Princess Margaret. Of approximately 530 patients, assuming 75% meet eligibility for treatment cycle; of these 398 about 25% may not speak English; 299 remain for recruitment; 10% may be cognitively impaired
leaving 269 patients eligible for participation / year (approximately 5 patients/week), as such six months is needed to recruit the sample.

4.5 b) Recruitment Procedure

Medical oncologists and nurses in chemotherapy clinics and the chemotherapy ambulatory care unit identified potential participants. Potential participants were then approached by the Research Coordinator (RC) during a clinic visit and asked if they would be interested in learning more about the study. For those who expressed interest, the RC used plain language to explain the objectives of the study, the potential benefits and risks, as well as the responsibilities of participation in the study. A list tracking all potential participants was maintained to ensure that the RC did not approach patients at multiple times to invite participation. The tracking list was also used to record the response/non-response rate. Those that agreed to participate were asked to provide informed consent and were provided with a copy of the consent form for their records. Following informed consent, The RC administered the questionnaire in interview format. All sections of the questionnaire were interviewer administered with the exception of the health literacy measure (S-TOFHLA), because each participant had to complete it independently. The RC was present in-clinic during self-administration of the S-TOFHLA questionnaire in case study participants had questions or required clarification. Completion of the whole survey took between forty and fifty minutes. The RC recorded the reasons that patients stated for declining participation in the study.

4.5 c) Feasibility

Questionnaires were reviewed weekly to ensure that an appropriate number of completed questionnaires were collected and to monitor the response rate and to minimize missing data. The study team experienced a high response rate (59.1%). This may be attributed to relevance of the surveys to study participants and also the long wait times for appointments, which leaves patients available to participate.

Individuals with inadequate health literacy could be hesitant to participate in research due to the potential for exposure and also distrust [200]. As such, it was anticipated that the sample could be biased toward individuals with marginal to high health literacy levels and few with inadequate health literacy levels. To mitigate this potential for bias, data
collection was done through self-administration so that participants would not have to reveal any potential challenges with reading or writing. The sample consisted of cancer patients undergoing chemotherapy, therefore the potential for them to feel unwell and not wish to participate was anticipated. To attempt to reduce this “healthy worker bias”, short versions of validated instruments were selected when possible to decrease the time commitment and effort required.

4.5 d) Sampling Procedure

A convenience sample of patients was recruited. On scheduled days, medical oncologists and nurses from the systemic therapy unit, where chemotherapy is administered, identified all eligible patients. The RC approached all eligible patients about participation in the study.

4.6 Data Collection

4.6 a) Measures & Psychometric Properties

To reduce misclassification bias, where possible, scales were chosen that had been validated in cancer populations to measure the independent variables [201, 202], and dependent variables [79, 203]. All instruments have good internal consistency reliability (Cronbach’s alpha = > 0.8). The variable table is provided in the Appendices (Table 1).

**Health Literacy: Test of Functional Health Literacy (TOFHLA)**

The primary independent variable, health literacy, was measured using the Short Test of Functional Health Literacy in Adults (S-TOFHLA) scale [119]. The S-TOFHLA is a validated 36-item questionnaire that measures functional health literacy in adult populations [119]. Participants were given up to 7 minutes to complete the S-TOFHLA. The S-TOFHLA was developed using a sample of patient education materials, instructions for diagnostic tests, prescription bottle labels, and patient informed consent forms from two hospitals in the United States. The test itself was developed using a convenience sample of 403 patients and it has been used extensively in health literacy research [26]. The reading comprehension part is a 36-item test using the modified Cloze procedure. Every fifth to seventh word in a passage is omitted and the reader must select the most appropriate word from four possible choices, only one of which is correct. The other three word choices are similar to the correct word but are either grammatically or
contextually incorrect. The reading passages were selected from instructions for preparation for an upper gastrointestinal procedure, the patient rights and responsibility section of an American Medicaid application form, and a standard hospital consent form.

The S-TOFHLA produces a continuous score ranging from 0-36. Scores that range between 1-16 fit into the inadequate health literacy threshold, scores that range between 17-22 fit into the marginal health literacy category, and scores that range between 23-36 fit into the adequate health literacy category. Note that although three categories are provided in the S-TOFHLA to provide reference categories to continuous scores, Health Literacy is treated as a continuous variable in all analyses.

Reliability was calculated by both split-half and internal consistency measures, using equal-length Spearman-Brown and Cronbach’s alpha formulas. Reliability was calculated using all 36 items of the S-TOFHLA and both the Spearman-Brown equal-length coefficient (an estimate of test-retest reliability) and the Cronbach’s alpha measure of internal consistency were excellent (Spearman-Brown 0.92, Cronbach’s alpha 0.98). Using actual hospital materials for reading comprehension enhanced content validity. Determining Spearman’s rank correlation between the S-TOFHLA and other well-known health literacy instruments, the WRAT-R and the REALM, tested concurrent validity. Correlations of the S-TOFHLA with the REALM and the WRAT-R were 0.84 and 0.74 respectively (p< 0.001 by Spearman’s rank correlation) [119].

Literacy experts have shown that functional health literacy can be context specific [204] and a review of health literacy measures in cancer suggests that because of this, thought should be given to choice of measures used in the cancer context [205]. This means that an individual’s reading comprehension level could be adequate in one context and marginal or inadequate in another. The S-TOFHLA, includes passages that relate to diagnostic test preparation and the completion of medical forms. Although it is not cancer specific, the passages are broad enough to be relevant to many medical contexts. The REALM, a word recognition test of health literacy level has been used in the cancer context more than the S-TOFHLA, however, the REALM is also not cancer specific but requires less time to administer [205].
**Self-Efficacy: Cancer Behaviour Inventory - Brief (CBI-B)**

The independent variable, self-efficacy, was measured using the Cancer Behaviour Inventory-Brief (CBI-B) [101]. The Cancer Behaviour Inventory-Brief (CBI-B) is a validated measure that measures self-efficacy for coping with cancer. The CBI-B asks participants to rate how confident they are that they can accomplish 12 different cancer coping behaviours. Each behaviour is rated on a 0-9 numeric rating scale with 1-3 being “not at all confident”, 4-6 being “moderately confident”, and 7-9 being “totally confident”. A component score is taken from the arithmetic mean of the 12-items. The CBI-B has been shown to have good internal consistency reliability (Cronbach’s alpha = .84 to .88) [206].

**Chemotherapy Self-Management: Leuven Questionnaire for Patient Self-Care During Chemotherapy**

The first dependent variable, Chemotherapy Self-Management, was measured using the Leuven Questionnaire for Patient Self-Care During Chemotherapy scale (L-PaSC) [79]. The L-PaSC is a 22-item instrument with 7 themes expressing the most relevant aspects of patient self-care during chemotherapy including symptom management, performance of self-care behaviours in daily life, adherence to oral chemotherapy and supportive medication, and also received self-care advice. Adherence to self-care for everyday life is assessed on a 5-point Likert scale. Questions about oral chemotherapy, supportive medication, and symptom relieving self-care, visual analogue scales from 0-100% are used. All of the remaining questions regarding symptom management are multiple-choice.

Construction of the instrument was done in three phases: definition of the constructs, instrument development, and psychometric evaluation. The L-PaSC has acceptability validity and reliability: it has been shown to have good internal consistency reliability with a Cronbach’s alpha coefficient of 0.76 and the reliability value based on a Rasch model is 0.77 at an average self-care level. Exploratory factor analysis was performed to investigate the underlying structure of the questionnaire. A 2-factor model explained 61.1% of the common variance of respondent answers and thus content validity of the scale and the individual items is excellent [79].
Health Service Utilization: Stanford Patient Education Research Centre 
Scale for Health Services Utilization

The second dependent variable, health service utilization, was measured using the Stanford Patient Education Research Centre scale for Health Services Utilization [203]. This scale includes four questions: In the last 6 months, how many times did you visit a physician?; how many times did you go to the emergency room?; how many different times did you stay overnight or longer in a hospital?; and how many total nights did you spend in the hospital? The questions will be modified to ask about health service use for the duration of chemotherapy rather than about the prior 6 months. Each item has been shown to have good internal consistency reliability (Cronbach's alpha = 0.76, 0.94, 0.89, and 0.97 respectively) [203]. Patient recall is not a concern for this study since patients are only asked to recall health service use over a very short period of time. Provided that patient self-report of health service utilization is less than 6 months, it is generally found to be reliable [207]. Thus, patient self-report of health service use will not be validated against medical records.

Symptom Severity and Symptom Interference: MD Anderson Symptom Inventory

The potential confounder variables, symptom severity and symptom interference, were measured using the MD Anderson symptom inventory (MDASI) [77]. The MDASI is a 13-item instrument (symptom severity) and a 6-item instrument (symptom interference) that assesses the severity of multiple symptoms and the impact of symptoms on daily functioning. It is a multi-symptom patient-reported outcome measure (PROM) for clinical and research use. The MDASI’s 13 core symptom severity items include those found to have the highest frequency and/or severity in patients with various cancers and treatment types and include: pain, fatigue, nausea, disturbed sleep, distress (emotional), shortness of breath, lack of appetite, drowsiness, dry mouth, sadness, vomiting, difficulty remembering, and numbness or tingling. The MDASI’s symptom interference items include general activity, mood, work, relations with other people, walking and enjoyment of life. Each activity is rated on a 0-10 numeric rating scale with 0 being “did not interfere” and 10 being “completely interfered”. A component score is taken from the arithmetic mean of the 6 items. The MDASI has several advantages over other symptom-assessment scales in that it applies broadly across cancer types and treatments, it is easy
for patients to complete and takes approximately five minutes per instrument. The MDASI measures the severity of multiple symptoms and the impact of symptoms on daily functioning during the last 24 hours.

Construction of the instrument involved content, criterion, and construct validity and reliability (internal consistency and test-retest). It further involved patient input in the selection of items and post–test-construction cognitive debriefing to determine how intuitive, understandable, and relevant the items of the instruments were to patients. The MDASI has good internal consistency reliability (Cronbach’s alpha ranges from 0.82 to 0.94). A copy of the survey is provided in the Appendices.

4.7 Statistical Analysis

The following analyses were conducted to answer each research question. Greater detail is supplied in the Results Chapter.

Tests for several statistical assumptions were conducted. The data were first checked for missing data, outliers, and other departures from normality; the internal consistency reliability for all measurements was also calculated. For all tests, the alpha value was <0.05 as the a priori assigned level of statistical significance.

Descriptive statistics were used to summarize the distribution of health literacy scores to answer research question one: What is the distribution of health literacy scores among cancer patients receiving chemotherapy at the Princess Margaret Cancer Centre?

Bivariate analysis was conducted to determine associations between socio-demographic variables and health literacy levels to answer research question two: What are the associations between Health Literacy and socio-demographic variables, self-efficacy, symptom severity and symptom interference?. To determine if there was an association between the health literacy score and continuous socio-demographic variables, Pearson correlation tests were employed, or Spearman correlation [Wilcoxon Rank Sum test] when assumptions of normality were not met. To determine the significance of association for binary or categorical socio-demographic variables, chi-squared tests were employed, or Kruskal-Wallis tests if the assumptions of normality were not met.
Regression Analysis was conducted to determine associations between health literacy and the dependent variables to answer research questions three and four: Is health literacy level associated with chemotherapy self-management independent of symptom severity, symptom interference and self-efficacy? Is health literacy level associated with health service utilization independent of symptom severity, symptom interference, self-efficacy and independent of chemotherapy self-management behaviours. Two hierarchical linear regression models were fit, one for each dependent variable (chemotherapy self-management and health service utilization) were applied.

4.8 Ethical Considerations

Approval for this study was obtained from the Princess Margaret Cancer Centre/University Health Network Research Ethic Board (REB) and the University of Toronto Research Ethics Board. Consent was implied by survey completion. All participants were assured of anonymity of their responses. All data gathered from the study were locked in a secure office to maintain confidentiality. Each participant was assigned a code number that was stored in a separate locked file and accessed only by the researcher for confidentiality. All information on computer files was password protected and saved on a locked memory disk. Group statistics only were reported and no individual participant was identified from reported results. All data will be kept for seven years.
Chapter 5: Results

This Chapter is divided into four major sections. The first section provides information about the sample and descriptive data about the participant characteristics including socio-demographic information, cancer-related characteristics and health literacy scores in the sample (Research Question 1: What is the distribution of Health Literacy scores in cancer patients receiving chemotherapy). The second section describes the relationship between socio-demographic variables, self-efficacy, symptom severity and symptom interference (Research Question 2: What are the associations between Health Literacy and socio-demographic variables, self-efficacy, symptom severity and symptom interference). The third section includes the results of hierarchical linear regression models (Research Question 3: Is health literacy level associated with chemotherapy self-management independent of symptom severity, symptom interference and self-efficacy? Research Question 4: Is health literacy level associated with health service utilization independent of symptom severity, symptom interference, self-efficacy and independent of chemotherapy self-management?). The fourth section includes a summary of the main results.

5.1 Derivation of the Sample

Over the six-month period of data collection, based on study eligibility criteria, the total number of participants recruited to the study was 213 and the total number of individuals approached was 642. The response rate was 59.1%. Of those approached, 232 individuals did not meet inclusion criteria and this was either because they were in their first cycle of chemotherapy (n=79) (the inclusion criteria stated that participants must be in at least the second cycle of chemotherapy), or they were receiving therapies other than chemotherapy (n=153) (this included immunotherapy and hormone therapy). One hundred ninety-seven individuals declined to participate in the study. The reasons stated were that individuals did not speak English (n = 6), were sleeping or felt unwell (n=44) or that there was insufficient time left during their clinic visit to complete the survey (n=147). Two participants were excluded from the analysis as they were only able to complete the socio-demographic section of the questionnaire. Figure 5 shows a flow chart of the enrollment process.
5.2 Data Analyses

Data were analyzed using SPSS Version 20.0 (SPSS Inc.). To test for several statistical assumptions, the data were first checked for missing data, outliers and other departures from normality; the internal consistency reliability for all measures was also calculated. For all applicable tests, a 95% confidence interval was used and a p value of < 0.05 was the a priori assigned level of significance.

5.2 a) Evaluation of Missing Data, Outliers, and the Normality of Data Distributions

There were no missing data in the instruments included in the questionnaire package and less than 1% missing data in responses to socio-demographic questions. According to
Schafer and Bennett, methods to handle missing data are not required when less than 5-10% of data is missing [208, 209]. Extreme outliers were detected through visual inspection of boxplots for the Health Service Utilization questions. Outliers were addressed through 95% Winsorization [210]. Winsorization is the transformation of statistics by limiting extreme outliers when justification for doing so is merited [210].

Non-normality was detected using Shapiro-Wilk tests; variables with positively skewed distributions included the primary dependent variable: Health Service Utilization questions. Four dependent variables - Visits to Healthcare Provider, Visits to Emergency Department, Number of Hospitalizations and Number of Nights Spent in Hospital since Start of Chemotherapy - underwent logarithmic transformation and the resultant transformed distributions approximated normal. As such, the Health Service Utilization data used in all subsequent analyses were log-transformed and reported as logs.

5.2 b) Variable Transformations and Assumption Checking

In preparation for hierarchical linear regression, the following tests and variable transformations were conducted to ensure that all assumptions of regression models were met. The tests showed that all assumptions were met. The dependent variables were measured on continuous scales (chemotherapy self-management and health service utilization) and more than two independent variables were included in each of the models. Scatterplots and partial regression plots were performed to ensure that there was a linear relationship between the dependent variables and each independent variable, that there were no significant outliers, and that the distributions were approximately normal. Correlation matrices were used to confirm the strength and direction of relationships, specifically, the relationship between the dependent variables and independent variables as well as the relationship between each independent variable in order to determine which variables to include in the regression analyses. The Durbin-Watson test statistic was used to test the independence of observations. Bartlett’s test was used to determine homoscedasticity. Multicollinearity among variables was assessed by examining both tolerance levels and variance inflation factors (VIF). Tolerance values less than 0.10 is an indicator of multicollinearity or if the VIF is greater than 10 [211].
5.2 c) Reliability of Instruments

Internal consistency reliability (Cronbach’s alpha) was used to evaluate the reliability of all instruments in this study [212]. Table 1 outlines the Cronbach’s alpha values for all instruments included in the questionnaire package. The Cronbach’s alpha for all measures is higher than 0.7 which indicates acceptable reliability, and all tested are 0.8 or higher which indicates good reliability [212]. Note that the measures of health service utilization were single-items that were validated through test-re-test reliability [203].

Table 1 Cronbach’s Alpha Value for Instruments that Comprise the Questionnaire

<table>
<thead>
<tr>
<th>Name of Instrument</th>
<th>Item(s)</th>
<th>Internal Consistency Reliability (Cronbach’s Alpha, $\alpha$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short - Test of Functional Health Literacy Assessment</td>
<td>36</td>
<td>.904</td>
</tr>
<tr>
<td>(S-TOFLHA)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer Behaviour Inventory - Brief (CBI-B)</td>
<td>14</td>
<td>.868</td>
</tr>
<tr>
<td>MD Anderson Symptom Inventory – Symptom Severity (MDASI – SS)</td>
<td>13</td>
<td>.817</td>
</tr>
<tr>
<td>MD Anderson Symptom Inventory – Symptom Interference (MDASI – SI)</td>
<td>6</td>
<td>.876</td>
</tr>
</tbody>
</table>

5.3 Section 1: Descriptive Statistics

5.3 a) Characteristics of Participants

Participant socio-demographic characteristics are presented in Table 2. The mean age was 59 years (95% CI [56.77, 60.50], $SD = 13.709$) with a range from 18 to 87 years. The majority of participants were women (59.2%; men: 40.8%). Most participants attended college or university (n = 139, 65.5%) and only a very small percentage of participants had less than high school education (n = 9, 4.3%). A large number of participants preferred not to share household income (n = 56, 26.4%). About a quarter of participants had household incomes greater than $100,000 (n = 55, 25.9%) with a small number of household incomes reported below $25,000 (n = 20, 9.4%). A large proportion of participants were working full-time when diagnosed with cancer (n = 116, 54.7%) while approximately one quarter of participants were retired (n = 55, 25.9%). Most participants lived with at least one other person (n = 173, 81.7%) and a small number
lived alone (n = 35, 16.5%). The majority of participants were Caucasian (n = 156, 73.9%) followed by Chinese (n = 14, 6.6%). The other population groups represented just over 10% of all study participants. A little more than half of the participants were born in Canada (n = 116, 54.7%) and the majority of participants spoke English at home (n = 180, 84.9%). See Appendices for listing of all countries of birth.

Table 2 Socio-Demographic Information (N=211)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-40</td>
<td>22</td>
<td>10.4</td>
</tr>
<tr>
<td>41-64</td>
<td>110</td>
<td>52.1</td>
</tr>
<tr>
<td>65-90</td>
<td>79</td>
<td>37.4</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>125</td>
<td>59.2</td>
</tr>
<tr>
<td>Male</td>
<td>86</td>
<td>40.8</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College/University to graduate school</td>
<td>139</td>
<td>65.5</td>
</tr>
<tr>
<td>High school to some college/university</td>
<td>62</td>
<td>29.3</td>
</tr>
<tr>
<td>Grade school to some high school</td>
<td>9</td>
<td>4.3</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>.5</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>56</td>
<td>26.4</td>
</tr>
<tr>
<td>$100,000+</td>
<td>55</td>
<td>25.9</td>
</tr>
<tr>
<td>$50,000 - $74,999</td>
<td>30</td>
<td>14.2</td>
</tr>
<tr>
<td>$25,000- $49,999</td>
<td>28</td>
<td>13.2</td>
</tr>
<tr>
<td>Less than $25,000</td>
<td>20</td>
<td>9.4</td>
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<td>$75,000 - $99,999</td>
<td>19</td>
<td>9.0</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>2.4</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working Full-Time</td>
<td>116</td>
<td>54.7</td>
</tr>
<tr>
<td>Retired</td>
<td>55</td>
<td>25.9</td>
</tr>
<tr>
<td>Working Part-Time</td>
<td>20</td>
<td>9.4</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>2.8</td>
</tr>
<tr>
<td>Student</td>
<td>5</td>
<td>2.4</td>
</tr>
<tr>
<td>Homemaker</td>
<td>4</td>
<td>1.9</td>
</tr>
<tr>
<td>On Disability</td>
<td>2</td>
<td>.9</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
<td>.9</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>.5</td>
</tr>
<tr>
<td>Number of individuals in household</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>94</td>
<td>44.5</td>
</tr>
<tr>
<td>More than two:</td>
<td>79</td>
<td>37.4</td>
</tr>
<tr>
<td>One</td>
<td>35</td>
<td>16.5</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>1.4</td>
</tr>
</tbody>
</table>
Population group
White  156  74
East Asian  27  12.8
South Asian  8  3.8
Latin American  7  3.3
Arab  6  2.8
Black  6  2.8
Aboriginal  1  .5

Country of birth
Canada  116  54.7
Other  93  43.9
Missing  2  .9

Language spoken at home
English  180  84.9
Other  31  14.6

5.3 b) Cancer-Related Characteristics

Participants’ cancer-related clinical characteristics are shown in Tables 3 and 4. These include cancer type and whether participants were receiving concurrent radiation therapy.

Cancer Site

Cancers are described by the primary site of origin and these are presented in Table 3. Nine different cancer sites were included with gynecologic cancers being the most common in this sample (n = 50, 23.7%). Gynecologic cancers were followed in number by cancers of the gastrointestinal tract (n = 43, 20.4%), hematologic cancers (n = 39, 18.5%), breast cancer (n = 27, 12.8%), genitourinary cancers (n = 24, 11.4%), lung cancer (n = 12, 5.7%). The smallest percentage of the population included cancers of the head and neck (n = 5, 2.4%), melanoma (n = 5, 2.4%) and sarcoma (n = 4, 1.9%). Two participants indicated that they did not know what cancer they had (n = 2, 0.9%). In total, thirty-one distinct cancer types were included with ovarian cancer being the most common in this sample (n = 37, 17.5%) followed by breast (n = 27, 12.7%) and lymphoma (n = 22, 10.4%).
Table 3 Cancer Site (N=211)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gynecologic</td>
<td>50</td>
<td>23.7</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>43</td>
<td>20.4</td>
</tr>
<tr>
<td>Hematologic</td>
<td>39</td>
<td>18.5</td>
</tr>
<tr>
<td>Breast</td>
<td>27</td>
<td>12.8</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>24</td>
<td>11.4</td>
</tr>
<tr>
<td>Lung</td>
<td>12</td>
<td>5.7</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>5</td>
<td>2.4</td>
</tr>
<tr>
<td>Melanoma</td>
<td>5</td>
<td>2.4</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>4</td>
<td>1.9</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
<td>.9</td>
</tr>
</tbody>
</table>

**Chemotherapy Drugs**

Chemotherapy drugs can be given on their own or, as is done more often, several chemotherapy drugs can be given together. Chemotherapy may also be given together with other drug treatments, such as biological therapy. Among the sample, approximately one quarter of participants received a single chemotherapy drug (n = 57, 27.9%) and the remaining participants received multiple chemotherapy drugs (n = 154, 67.9%). The most common single chemotherapy drug given was Paclitaxel (n = 15, 7.1%) and the most common multiple chemotherapy drugs received were Paclitaxel and Carboplatin together (n = 29, 13.8%). See Appendices for listing of chemotherapy drugs.

**Chemotherapy and Concurrent Radiation Therapy**

Chemotherapy can be delivered concurrently with radiation therapy for certain indications. Among the sample, most participants were not receiving concurrent radiation therapy (91.9%).

Table 4 Received Concurrent Radiation Therapy

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concurrent radiation therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>194</td>
<td>91.9</td>
</tr>
<tr>
<td>Yes</td>
<td>17</td>
<td>8.1</td>
</tr>
</tbody>
</table>

Research Question 1. What is the distribution of health literacy scores among cancer patients receiving chemotherapy at the Princess Margaret Cancer Centre?

The hypothesis tested in this analysis is as follows:
Hypothesis 1: Health Literacy scores will be clustered on the low end of the measure (inadequate health literacy).

**Health Literacy**

The Short Test of Functional Health Literacy (S-TOFHLA) is a test of adult reading comprehension skills with questions that are situated within the context of healthcare. It consists of reading passages with fill-in-the-blanks as well as multiple-choice questions. A composite numeric score is calculated based on the number of correct answers. Numeric scores are grouped into one of three threshold categories of health literacy. Health Literacy scores range between 1-36 (with 36 being a perfect score). Scores that range between 1-16 fit into the inadequate health literacy threshold, scores that range between 17-22 fit into the marginal health literacy category, and scores that range between 23-36 fit into the adequate health literacy category. Note that although three categories are provided in the S-TOFHLA to provide reference categories to continuous scores, Health Literacy was treated as a continuous variable in all analyses.

The analysis did not support the Hypothesis that most participants would have inadequate Health Literacy scores. The majority of participants had adequate health literacy (n = 199, 94.3%). Table 5 presents the health literacy scores by sub-score. The mean score was (M=32.76, 95% CI [31.9, 33.5], SD= 5.834). This distribution was negatively skewed (Skewness -3.317, Standard Error .167) meaning that the scores were clustered at the high end of the measure. See Figure 2 for histogram.

<table>
<thead>
<tr>
<th>Item</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate (23-36)</td>
<td>199</td>
<td>94.3</td>
</tr>
<tr>
<td>Marginal (17-22)</td>
<td>6</td>
<td>2.8</td>
</tr>
<tr>
<td>Inadequate (1-16)</td>
<td>6</td>
<td>2.8</td>
</tr>
</tbody>
</table>
Self-Efficacy

The Cancer Behaviour Inventory-Brief (CBI-B) measures self-efficacy for coping with cancer. The CBI-B asks participants to rate how confident they are that they can accomplish 14 different cancer coping behaviours. Each behaviour is rated on a 0-9 numeric rating scale with 1-3 being “not at all confident”, 4-6 being “moderately confident”, and 7-9 being “totally confident”. A component score was taken from the arithmetic mean of all 14-items. Note that although three categories are provided in the CBI-B to provide reference categories to continuous scores, Self-efficacy was treated as a continuous variable in all analyses.

The scores ranged from 3.9 to 9 with the lower end of the scale indicating lower self-efficacy ($M=7.23$, 95% CI [7.1, 7.4], $SD=1.19$). Table 6 presents self-efficacy scores by
sub-score. See Table 7 for self-efficacy scores on each item. The distribution was approximately normal.

**Table 6 Cancer Behavior Inventory-Brief: Self-Efficacy (N=211)**

<table>
<thead>
<tr>
<th>Item</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totally confident (7-9)</td>
<td>127</td>
<td>60.2</td>
</tr>
<tr>
<td>Moderately confident (4-6)</td>
<td>83</td>
<td>39.3</td>
</tr>
<tr>
<td>Not confident (1-3)</td>
<td>1</td>
<td>00.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintaining independence</td>
<td>1</td>
<td>9</td>
<td>7.11</td>
<td>2.071</td>
</tr>
<tr>
<td>Maintaining a positive attitude</td>
<td>1</td>
<td>9</td>
<td>7.34</td>
<td>1.850</td>
</tr>
<tr>
<td>Maintaining a sense of humour</td>
<td>1</td>
<td>9</td>
<td>7.73</td>
<td>1.650</td>
</tr>
<tr>
<td>Expressing feelings about cancer</td>
<td>1</td>
<td>9</td>
<td>7.00</td>
<td>2.196</td>
</tr>
<tr>
<td>Putting things out of my mind at times</td>
<td>1</td>
<td>9</td>
<td>6.64</td>
<td>2.139</td>
</tr>
<tr>
<td>Maintaining activities (work, home, hobbies, social)</td>
<td>1</td>
<td>9</td>
<td>6.43</td>
<td>2.233</td>
</tr>
<tr>
<td>Trying to be calm throughout treatments and not allowing scary thoughts to upset me</td>
<td>1</td>
<td>9</td>
<td>7.19</td>
<td>1.915</td>
</tr>
<tr>
<td>Actively participating in treatment decisions</td>
<td>1</td>
<td>9</td>
<td>7.88</td>
<td>1.721</td>
</tr>
<tr>
<td>Asking physicians questions</td>
<td>1</td>
<td>9</td>
<td>8.14</td>
<td>1.371</td>
</tr>
<tr>
<td>Seeking social support</td>
<td>1</td>
<td>9</td>
<td>7.09</td>
<td>2.338</td>
</tr>
</tbody>
</table>

**Table 7 Cancer Behavior Inventory-B, 2: Self-Efficacy (N=211)**

**Symptom Severity**

The MD Anderson Symptom Inventory (MDASI) assesses the severity of 13 symptoms at their worst in the last 24 hours on a 0-10 numeric rating scale with 0 being “not present” and 10 being “as bad as you can imagine”. A component score was taken from the arithmetic mean of all 13 items. The scores ranged between 0, indicating no severe symptoms to 6.2 indicating moderate to severe symptoms ($M= 1.9$, $95\%$ CI $[1.7, 2.1]$, $SD= 1.35$). See Table 8 for participant Symptom Severity scores. The distribution of the scores was approximately normal.
Table 8 MD Anderson Symptom Inventory: Symptom Severity (N=210)

<table>
<thead>
<tr>
<th>Item</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your pain at its worst</td>
<td>0</td>
<td>10</td>
<td>1.40</td>
<td>2.317</td>
</tr>
<tr>
<td>Your fatigue (tiredness) at its worst</td>
<td>0</td>
<td>10</td>
<td>3.30</td>
<td>2.545</td>
</tr>
<tr>
<td>Nausea at its worst</td>
<td>0</td>
<td>10</td>
<td>1.17</td>
<td>2.133</td>
</tr>
<tr>
<td>Your disturbed sleep at its worst</td>
<td>0</td>
<td>10</td>
<td>2.91</td>
<td>2.979</td>
</tr>
<tr>
<td>Your feelings of being distressed (upset) at its worst</td>
<td>0</td>
<td>10</td>
<td>2.20</td>
<td>2.621</td>
</tr>
<tr>
<td>Your shortness of breath at its worst</td>
<td>0</td>
<td>10</td>
<td>1.54</td>
<td>2.305</td>
</tr>
<tr>
<td>Your problem with remembering things at its worst</td>
<td>0</td>
<td>9</td>
<td>1.93</td>
<td>2.329</td>
</tr>
<tr>
<td>Your problem with lack of appetite at its worst</td>
<td>0</td>
<td>9</td>
<td>1.62</td>
<td>2.457</td>
</tr>
<tr>
<td>Your feeling drowsy (sleepy) at its worst</td>
<td>0</td>
<td>10</td>
<td>2.68</td>
<td>2.630</td>
</tr>
<tr>
<td>Your having a dry mouth at its worst</td>
<td>0</td>
<td>10</td>
<td>2.11</td>
<td>2.611</td>
</tr>
<tr>
<td>Your feeling sad at its worst</td>
<td>0</td>
<td>10</td>
<td>1.99</td>
<td>2.443</td>
</tr>
<tr>
<td>Your vomiting at its worst</td>
<td>0</td>
<td>10</td>
<td>.29</td>
<td>1.244</td>
</tr>
<tr>
<td>Your numbness or tingling at its worst</td>
<td>0</td>
<td>10</td>
<td>1.66</td>
<td>2.495</td>
</tr>
</tbody>
</table>

**Symptom Interference**

The MD Anderson Symptom Inventory (MDASI) measures how much symptoms interfere with 6 daily activities. These are general activity, mood, work, relations with other people, walking and enjoyment of life. Each activity is rated on a 0-10 numeric rating scale with 0 being “did not interfere” and 10 being “completely interfered”. A component score was taken from the arithmetic mean of the 6 items. The scores range from 0, indicating no interference with activities of daily living, and 9.2 indicating a high degree of interference ($M=2.42$, 95% CI [2.1, 2.7], $SD= 2.14$). Symptom interference scores are presented in Table 9. The distribution was positively skewed meaning that the majority of scores clustered at the lower end of the scale.
Table 9 MD Anderson Symptom Inventory: Symptom Interference (N=211)

<table>
<thead>
<tr>
<th>Item</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>General activity</td>
<td>0</td>
<td>10</td>
<td>2.83</td>
<td>2.897</td>
</tr>
<tr>
<td>Mood</td>
<td>0</td>
<td>10</td>
<td>2.35</td>
<td>2.586</td>
</tr>
<tr>
<td>Work (including work around the house)</td>
<td>0</td>
<td>10</td>
<td>3.16</td>
<td>3.119</td>
</tr>
<tr>
<td>Relations with other people</td>
<td>0</td>
<td>10</td>
<td>1.40</td>
<td>2.261</td>
</tr>
<tr>
<td>Walking</td>
<td>0</td>
<td>10</td>
<td>2.22</td>
<td>2.782</td>
</tr>
<tr>
<td>Enjoyment of life</td>
<td>0</td>
<td>10</td>
<td>2.59</td>
<td>2.644</td>
</tr>
</tbody>
</table>

**Chemotherapy Self-Management Behaviours**

The Leuven questionnaire for self-care during chemotherapy (L-PaSC) is a 22-item instrument that measures patient self-care knowledge and practice with a series of Likert scale (7), multiple choice (5+7) and visual analogue scale (3) responses. The Likert scale questions ask whether the participant performs 7 self-care behaviors and responses are coded as either correct or incorrect. An example of a Likert question from the L-PaSC is, “Do you drink 1.5 litres of water daily” and the response options include “Never, Most Not, Mostly, and Always”. The multiple-choice questions were posed in two different ways. The first set of multiple choice questions ask participants to indicate how they would respond in situations that involve the experience of five severe symptoms. An example of this type of multiple choice question from the L-PaSC is, “Indicate what you would do if you experienced sudden shortness of breath”. The second set of multiple choice questions has two-parts: the first includes questions relating to whether the participant experienced common symptoms associated with chemotherapy and the second part asks the participant to indicate what they did to treat it. An example of these multiple-choice questions is, “Since the start of chemotherapy treatment, how serious were the infections in the mouth?” The participants indicate first whether they experienced the symptom (Not applicable or Yes) and if they answered “Yes” they were asked to complete the second part, “If you had mouth infections, what did you do to treat it?” There are seven two-part multiple-choice questions. The visual analogue scale
(VAS) questions also ask two-part questions. The first part of the question asks whether the participant was given or prescribed something and the second part asks the participant to indicate a percentage that they adhered to the prescription. An example of a two-part VAS question in the L-PaSC is, “Does your treatment also include oral chemotherapy?” and if the participant indicates “Yes” they proceed to the second part, “What percentage of these doses have you taken correctly and at the right moment of the day?” There are three VAS questions. Each of the 22 items is scored and the total score is converted to a percentage. The scores ranged from 33% to 100% ($M=71, 95\% CI [69, 73], SD=13.9$). Chemotherapy self-management scores are presented in Table 10. The distribution was normal.

Table 10 Leuven Self-Care During Chemotherapy: Chemotherapy Self-Management Behaviours (N=209)

<table>
<thead>
<tr>
<th>Item</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drinker at least 1.5 liters of water a day</td>
<td>160</td>
<td>65.2</td>
</tr>
<tr>
<td>Ensuring good dental health and mouth hygiene by brushing your teeth at least twice a day</td>
<td>200</td>
<td>95.2</td>
</tr>
<tr>
<td>During chemotherapy until a few days after administration of the chemotherapy disposing of incontinence supplies, sanitary towels, tampons, etc. in a plastic bag</td>
<td>137</td>
<td>65.2</td>
</tr>
<tr>
<td>Avoiding contact with people with contagious diseases such as fever, chicken pox, cold sores or a cold</td>
<td>188</td>
<td>89.5</td>
</tr>
<tr>
<td>Taking your temperature when you feel ill</td>
<td>145</td>
<td>69</td>
</tr>
<tr>
<td>Taking medication without consulting a doctor</td>
<td>151</td>
<td>71.9</td>
</tr>
<tr>
<td>Taking measures to prevent you or your partner becoming pregnant</td>
<td>183</td>
<td>87.1</td>
</tr>
</tbody>
</table>
### Indicate what you do in the following situations

| Item                                                                 | Frequency | Percent |  |  |  |  |
|----------------------------------------------------------------------|-----------|---------|  |  |  |  |
| You suddenly feel short of breath after only a little physical activity. | - 63      | 146     | - 30.1 | 69.9 |
| You have a fever of 38.5. You have diarrhea three times per day.     | - 154     | 55      | - 73.7 | 26.3 |
| You have vomited five times in one single day and you can't keep any water down. | - 135     | 74      | - 64.6 | 35.4 |
| You feel pins and needles in your fingertips.                        | - 78      | 131     | - 37.3 | 62.7 |

### Does your treatment include chemotherapy in the form of tablets to be taken by mouth? If Yes:

| Item                                                                 | Frequency | Percent |  |  |  |  |
|----------------------------------------------------------------------|-----------|---------|  |  |  |  |
| What percentage of these doses have you taken correctly and at the right moment of the day? | 181 22    | 5 87    | 10.6 2.4 |
| What percentage of the medication to treat side effects have you taken correctly? | 27 158    | 24 12.9 | 75.6 11.5 |
| What percentage of the self-care advice you received or read about did you follow? | 29 118    | 62 13.9 | 56.5 29.7 |
| If you have (had) mouth infections, what did you do to treat it?     | 143 49    | 62 68.1 | 13.8 5.1 |
| If you have (had) a skin problem, what do (did) you do to treat it?  | 100 102   | 8 47.6  | 48.6 3.8 |
| If you are (were) nauseous, what do (did) you do to avoid or treat it? | 101 88    | 21 48.1 | 41.9 10.0 |
| If you have (had) constipation, what do (did) you do to avoid or treat it? | 69 127    | 14 32.9 | 60.5 6.7 |
| If you have (had) diarrhea, what do (did) you do to avoid or treat it? | 114 78    | 18 54.3 | 37.1 8.6 |
| If you suffer (suffered) from tiredness, what do (did) you do to deal with it? | 12 66     | 132 5.7 | 31.4 62.9 |
| If you have (had) pain, what did you do to stop it?                   | 71 91     | 48 33.8 | 43.3 22.9 |
**Health Service Utilization**

The Stanford Patient Education Research Centre Health Service Utilization questionnaire measures the number of health services utilized by an individual in the past 6 months. For the purpose of this research, the four questions contained within the questionnaire were modified to specify the timeline as “since the start of chemotherapy”. Each question was scored and 95% Winsorization was used to replace extreme data values with less extreme values. Prior to Winsorization, outlier data values were explored and the data values replaced were those found to be from participants undergoing stem cell transplants. The conditioning chemotherapy that stem cell transplant patients must undergo requires that they stay in hospital for a multitude of nights and report significantly different health service utilization data since start of chemotherapy than reported by participants not undergoing stem cell transplant. Winsorization was used to decrease the extreme outlier value to the next highest value in the data set. The number of visits made to a healthcare provider since start of chemotherapy ranged from 0 to 15 ($M=3.6$, 95% CI [3.1, 4.1], $SD=3.80$).

Table 10 presents the health service utilization scores. The distribution was positively skewed with the majority of scores clustered at the low end of the measure. The number of visits to the emergency department since start of chemotherapy ranged from 0 to 7 ($M=2.2$, 95% CI [1.8, 2.6], $SD=2.76$). The distribution was positively skewed with the majority of scores clustered at the low end of the measure. The total number of different times that a patient stayed overnight or longer in the hospital ranged from 0 to 6 ($M=1.1$, 95% CI [.85, 1.3], $SD=1.85$). The distribution was positively skewed with the majority of scores clustered at the low end of the measure. The total number of nights spent in the hospital since start of chemotherapy ranged from 0 to 16 ($M=2.6$, 95% CI [2.0, 3.2], $SD=4.55$). The distribution was positively skewed with the majority of scores clustered at the low end of the measure.
### Table 11 Health Service Utilization (N=211)

<table>
<thead>
<tr>
<th>Item</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the time since you started chemotherapy, how many times did you visit a healthcare provider outside of your regular appointments, including visits to the emergency department?</td>
<td>0</td>
<td>15</td>
<td>3.6</td>
<td>.4</td>
</tr>
<tr>
<td>In the time since you started chemotherapy, how many times did you go to a hospital emergency department?</td>
<td>0</td>
<td>7</td>
<td>2.2</td>
<td>.3</td>
</tr>
<tr>
<td>In the time since you started chemotherapy, how many different times did you stay overnight or longer in the hospital?</td>
<td>0</td>
<td>6</td>
<td>1.1</td>
<td>.2</td>
</tr>
<tr>
<td>In the time since you started chemotherapy, how many total nights did you spend in the hospital?</td>
<td>0</td>
<td>16</td>
<td>2.6</td>
<td>.5</td>
</tr>
</tbody>
</table>

#### 5.4 Section 2: Correlations

Research Question 2. What are the associations between Health Literacy and socio-demographic variables, self-efficacy, symptom severity and symptom interference?

The hypotheses tested in these correlation analyses are the following:

Hypothesis 2: Socio-demographic variables that are known to be associated with health literacy will also be correlated with health literacy in this sample, i.e., Health Literacy score, which is on a continuum from low to high, is significantly negatively correlated with older Age (Hypothesis 2a); Health Literacy score is positively correlated with Education (Hypothesis 2b) and Income scores (Hypothesis 2c); Health Literacy score is significantly positively correlated with Country of Birth (Hypothesis 2d) and Language Spoken at Home (Hypothesis 2e) (in that, participants born in Canada and those that speak English at home would have higher Health Literacy scores).

The socio-demographic variables that are associated with health literacy in the literature include Age, Education, Income, and Immigration Status (collected here as Country of Birth) and English language proficiency (collected here as Language Spoken at Home) [26]. The variables, Age, Education, Country of Birth, Language Spoken at Home and
Household Income, were categorical and were entered as ordinal variables in SPSS. An alpha level of .05 was used for all statistical tests.

5.4 a) Univariate Analysis

Kruskal-Wallis H tests were used to determine relationships between categorical socio-demographic variables and health literacy measured on a continuous scale. In addition, unlike Wilcoxon Rank Sum test and Mann-Whitney U, Kruskal-Wallis H tests were used to explore relationships between two variables within more than two groups.

**Assumptions of Kruskal-Wallis H Tests**

Prior to conducting Kruskal-Wallis H tests to determine relationships between Health Literacy and Age, Education, Country of Birth, Language Spoken at Home, and Household Income, it was determined that the four assumptions for using this test were met: 1) The dependent variable, Health Literacy was measured at the ordinal or continuous level; 2) the independent variables had at least two categories of independent groups; 3) all observations included in the analysis were independent; and 4) the distribution for each group on the independent variables have the same shape – that there was homogeneity of variance. To check the homogeneity of variance assumption, histograms were plotted for each group and skewness and kurtosis were determined to be similar. One-Way ANOVAs were run to test the assumption for homogeneity of variance and no statistically significant difference was found between group rank means.

The Kruskal-Wallis H is an omnibus test statistic that only shows whether there is a statistically significant difference between two groups but does not indicate where the significance is. As such, post-hoc tests were done to explore where the statistically significant differences were between each of the groups. Post-hoc tests were done on all independent variables that had a statistically significant difference in Health Literacy score between groups. The post-hoc tests were done by conducting the Kruskal-Wall H test repeatedly between each group [211].

The results of correlation analyses support the Hypothesis that the socio-demographic variables that are associated with Health Literacy in the literature are observed in this sample, with the exception of the Age.
**Age and Health Literacy**

Participant Age was divided into three groups. These groups were determined based on age categories defined by Statistics Canada and modified using standards articulated in the Journal of Clinical Oncology [213, 214]. Age categories defined by Statistics Canada are Children (Age 0-14), Youth (Age 15-24), Adults (Age 25-64) and Seniors (Age 65 and over). Since children were not included in the sample, this category was not used. In the oncology setting, the category Young Adult ranges between 18-40 and as such Statistics Canada categories Youth and Adult were combined. The years classified between Young Adult and Senior were categorized as 41-64 and Older adult as 65 and over which is consistent with Statistics Canada category, Senior. Group 1 included participants aged 18-40 years (n = 22), Group 2 included participants aged 41-64 years (n = 110), and Group 3 included participants aged 65-90 years (n = 79). The correlation results did not support Hypothesis 2a that Health Literacy score would be significantly negatively correlated to Age. A Kruskal-Wallis H test shows that there was no statistically significant difference in Health Literacy score between the different Age groups $\chi^2(2) = 3.798$, p=.150.

**Table 12 Mean Health Literacy Score by Age Threshold (N=211)**

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1: Age 18-40</td>
<td>34.23</td>
<td>3.74</td>
</tr>
<tr>
<td>Group 2: Age 41-64</td>
<td>32.85</td>
<td>6.04</td>
</tr>
<tr>
<td>Group 3: Age 65-90</td>
<td>32.24</td>
<td>6.00</td>
</tr>
</tbody>
</table>

**Education and Health Literacy**

Participant education levels were categorized into three threshold groups. These groups were determined using the education categories defined by Statistics Canada, National Household Survey [214]. Group 1 included participants with grade school to some high-school education (n = 9), Group 2 included participants who had completed high school to some college/university (n = 62), and Group 3 included participants with college or university or graduate school (n = 139).
Table 13 Mean Health Literacy Scores by Education Thresholds (N=208)

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1: Grade school to some high-school</td>
<td>24.44</td>
<td>12.48</td>
</tr>
<tr>
<td>Group 2: High-school to some college/university</td>
<td>31.52</td>
<td>6.48</td>
</tr>
<tr>
<td>Group 3: College/university to graduate school</td>
<td>33.88</td>
<td>4.21</td>
</tr>
</tbody>
</table>

The correlation results support Hypothesis 2b that Health Literacy score is positively correlated to Education. A Kruskal-Wallis H test shows that there was a statistically significant difference in Health Literacy score between the different Education groups $\chi^2 (2) = 25.271, p< 0.0005$ showing that those with higher education levels had higher Health Literacy scores. The mean Health Literacy score rank was 56.11 for Group 1 (Grade School or Some High-School), 80.65 for Group 2 (High-School or Some College/University), and 119.78 for Group 3 (College/University or Graduate school) that shows that those with higher levels of education also had higher health literacy scores. The effect size of education on health literacy scores was, however, small: $\eta^2 = .012$ which indicates that 1% of variability in rank score is accounted for by education group.

Post-hoc tests were conducted to determine where the statistically significant differences were between groups. Between Group analysis showed that there was no statistically significant difference between Group 1 (Grade School or Some High-School) and Group 2 (High-School or Some College/University), $\chi^2 (1) = 2.887, p=0.89$. There was a statistically significant difference in Health Literacy score between Groups 2 (High-School or Some College/University) and 3 (College/University or Graduate school), $\chi^2 (1) = 19.554, p<. 0005$, with a small effect size: $\eta^2 = .097$ and between Groups 1 (Grade School or Some High-School) and 3 (College/University or Graduate school), $\chi^2 (1) = 8.411, p=. 004$ also with a small effect size: $\eta^2 = .057$.

**Household Income and Health Literacy**

Household Income was categorized into six groups. These groups were based on the income categories defined by Statistics Canada [214]. Group 1 included participants with household incomes lower than $25,000 (n = 20), Group 2 included participants with household incomes between $25,000 to $49,999 (n = 28), Group 3 included participants with household incomes between $50,000 to $74,999 (n = 30), Group 4 included
participants with household incomes between $75,000 to $99,999 (n = 19), Group 5 included participants with household incomes greater than $100,000 (n = 55) and Group 6 included participants who indicated that they prefer not to answer the question (n = 56).

Table 14 Mean Health Literacy Score by Household Income (N=208)

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1: Less than $25,000</td>
<td>32.15</td>
<td>5.26</td>
</tr>
<tr>
<td>Group 2: $25,000 to $49,999</td>
<td>34.04</td>
<td>2.83</td>
</tr>
<tr>
<td>Group 3: $50,000 to $74,999</td>
<td>29.93</td>
<td>8.82</td>
</tr>
<tr>
<td>Group 4: $75,000 to $99,999</td>
<td>34.05</td>
<td>3.60</td>
</tr>
<tr>
<td>Group 5: $100,000 and above</td>
<td>34.09</td>
<td>4.84</td>
</tr>
<tr>
<td>Group 6: Prefer not to answer</td>
<td>32.04</td>
<td>6.39</td>
</tr>
</tbody>
</table>

The correlation results support Hypothesis 2c that Health Literacy score is positively correlated to Household Income. Kruskal-Wallis H tests show that there was a statistically significant difference in Health Literacy score between Household Income groups $\chi^2 (5) = 16.733$, p=.005 showing that most of the groups with higher incomes had higher health literacy scores. The mean rank Health Literacy score for Group 1 (Less than $25,000) was 92.40, Group 2 ($25,000-$49,000) was 108.75, Group 3 ($50,000-$74,000) was 77.78, Group 4 ($75,000-$99,000) was 115.39, Group 5 ($100,000+) 126.36, Group 6 (Prefer not to answer) 95.84. A small effect size was found $\eta^2 = .081$, which shows that 8% of variability in rank score, is accounted for by Household Income.

Post-hoc tests were conducted to determine where the statistically significant differences between mean rank Health Literacy scores were found between the 6 groups. Statistically significant differences between mean Health Literacy scores were found between the following groups: Group 1 (Less than $25,000) and 5 ($100,000+) $\chi^2 (1) = 5.029$, p=.025; Groups 2 ($25,000-$49,000) and 3 ($50,000-$74,000) $\chi^2 (1) = 4.251$, p=.039; Groups 3 ($50,000-$74,000) and 4 ($75,000-$99,000) $\chi^2 (1) = 4.936$, p=.026; Group 3 ($50,000-$74,000) and 5 ($100,000+) $\chi^2 (1) = 12.765$, p<.001; Group 5 ($100,000+) and 6 (Prefer not to answer) $\chi^2 (1) = 7.132$, p=.008.
Table 15 Post-Hoc Tests to Determine Where Statistically Significant Differences Between Mean Rank Health Literacy Score and Household Income Groups

<table>
<thead>
<tr>
<th>Item</th>
<th>Chi-Square</th>
<th>P-Value</th>
<th>Mean rank scores</th>
<th>Eta-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1 (Less than $25,000) Group 5 ($100,000+)</td>
<td>$\chi^2$ (1) = 5.029</td>
<td>p = .025</td>
<td>29.05</td>
<td>$\eta^2 = 0.68$</td>
</tr>
<tr>
<td>Group 2 ($25,000-$49,000) Group 3 ($50,000-$74,000)</td>
<td>$\chi^2$ (1) = 4.251</td>
<td>p = .039</td>
<td>34.16</td>
<td>$\eta^2 = 0.75$</td>
</tr>
<tr>
<td>Group 3 ($50,000-$74,000) Group 4 ($75,000-$99,999)</td>
<td>$\chi^2$ (1) = 4.936</td>
<td>p = .026</td>
<td>21.45</td>
<td>$\eta^2 = 0.103$</td>
</tr>
<tr>
<td>Group 3 ($50,000-$74,000) Group 5 ($100,000 and above)</td>
<td>$\chi^2$ (1) = 12.765</td>
<td>p &lt; .001</td>
<td>30.45</td>
<td>$\eta^2 = 0.152$</td>
</tr>
<tr>
<td>Group 5 ($100,000 and above) Group 6 (Prefer not to answer)</td>
<td>$\chi^2$ (1) = 7.132</td>
<td>p = .008</td>
<td>63.95</td>
<td>$\eta^2 = 0.65$</td>
</tr>
</tbody>
</table>

Country of Birth and Health Literacy

As mentioned above, Country of Birth is a variable that is meant to represent immigration status. Immigrant status is a known predictor of low Health Literacy [26, 205]. Country of Birth was divided into two groups. Group 1 included participants who were born in Canada to indicate that the participants did not immigrate (n = 116) and Group 2 included participants born outside of Canada to indicate that they had immigrated. Among Group 2 fifty-two different countries were represented (n = 93).

Table 16 Mean Health Literacy Score by Country of Birth (N=209)

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1: Canada</td>
<td>33.79</td>
<td>3.665</td>
</tr>
<tr>
<td>Group 2: Country other than Canada</td>
<td>31.46</td>
<td>7.602</td>
</tr>
</tbody>
</table>

The correlation results support Hypothesis 2d that Health Literacy score is positively correlated to Country of Birth. A Kruskal-Wallis H test shows that there was a statistically significant difference in Health Literacy score between the Country of Birth groups $\chi^2 (1) = 7.295$, p = .007 showing that those born in Canada had higher health literacy scores than those born in a country outside of Canada. The mean rank health literacy score for Group 1 (Canada) was 114.86 and 92.70 for Group 2 (Other). A small effect size was found $\eta^2 = .035$ that showed that 4% of variability in rank score is accounted for by country of birth.
**Language Spoken at Home and Health Literacy**

As mentioned above, Language Spoken at Home is a variable that represents English proficiency. In English speaking countries, being proficient in English is known to predict higher health literacy and this is explained in part, because healthcare communication is conducted in English [26, 195]. For this analysis, Language Spoken at Home was divided into two groups. Group 1 included participants who spoke English at home (n = 180) and Group 2 included participants who spoke languages other than English at home (n = 31).

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1: English at home</td>
<td>33.61</td>
<td>3.968</td>
</tr>
<tr>
<td>Group 2: Language other than English at home</td>
<td>27.87</td>
<td>10.739</td>
</tr>
</tbody>
</table>

The correlation results support Hypothesis 2e that Health Literacy score is correlated to Language Spoken at Home. A Kruskal-Wallis H test shows that there was a statistically significant difference in Health Literacy score between the Language Spoken at Home groups $\chi^2 (1) = 5.871$, p=.015 suggesting that those who spoke English at home had higher health literacy scores than those who spoke a language other than English at home. The mean rank Health Literacy score for Group 1 (English) was 110.12 and 82.08 for Group 2 (Other). A small effect size was found: $\eta^2 = .027$ which showed that 3% of variability in rank score is accounted for by Language Spoken at Home.

**Correlations: Health Literacy, Symptom Severity, Symptom Interference, Chemotherapy Self-management and the Four Items of Health Service Utilization**

The following correlation analyses were conducted to determine which independent variables to include in the multivariate regression analyses. Independent variables not statistically significantly associated with the dependent variables were omitted from regression models that relate to Research Questions 3 and 4.

The hypotheses tested with these correlation analyses are the following:

Hypothesis 3: Health Literacy will be correlated with Self-Efficacy, Symptom Severity, Symptom Interference and with the dependent variables (Chemotherapy Self-Management and Health Service Utilization) in this sample, i.e., Health Literacy score is
positively correlated with Self-Efficacy score (Hypothesis 3a); Health Literacy score is negatively correlated with Symptom Severity score (Hypothesis 3b), Symptom Interference score (Hypothesis 3c), Chemotherapy Self-Management score (Hypothesis 3d) and the Health Service Utilization scores (Hypothesis 3e).

Pearson product-moment correlation coefficient tests were used to explore correlations and the strength of the significant correlations between independent variables (Health Literacy, Self-Efficacy, Symptom Severity and Interference) and dependent variables (Chemotherapy Self-Management and the four Health Service Utilization questions (Number of: Visits to Healthcare Provider, Visits to Emergency Department, Hospitalizations, and Nights Spent in Hospital Since the Start of Chemotherapy)

**Assumptions of Pearson Product-Moment Correlation Coefficient**

Prior to conducting Pearson correlation tests to determine the relationship between Health Literacy, Self-Efficacy, Symptom Severity, Symptom Interference, Chemotherapy Self-Management and the four questions of Health Service Utilization, it was determined that the assumptions for running this test were met with the exception of the Health Service Utilization variables. As such, Kendall’s tau-b tests were used to explore the relationship between Health Literacy and Health Service Utilization. All other variables met the assumptions for Pearson correlation. These assumptions are:

1) Variables are measured at the interval or ratio level, health literacy and all independent variables were measured at the continuous level,

2) A linear relationship is shown between all variables,

3) No significant outliers and data are normally distributed or approximately normally distributed. Several studies have demonstrated that when a sample size is >50, normality is no longer required, see Fowler (1984) and Edgell (1987) [215, 216].

The Health Service Utilization items did not meet the second assumption of Pearson correlation and as such, Kendall’s tau-b tests were conducted to explore the relationship between Health Literacy and Health Service Utilization. The results of the Kendall’s tau-b analysis are reported below the Pearson correlation results.
The correlation results do not support Hypothesis 3a. Results from the Pearson correlation analysis showed that there is no relationship between Health Literacy and Self-Efficacy $r = -.032$, $n= 211$, $p= .644$. The correlation results support Hypothesis 3b) that there is a negative correlation between Health Literacy and Symptom Severity. There is a statistically significant weak negative correlation between Health Literacy and Symptom Severity $r = -.141$, $n= 210$, $p= .041$. This shows that changes in Health Literacy scores are associated with changes in Symptom Severity scores in the opposite direction. As Health Literacy scores decrease, Symptom Severity scores increase. The correlation results also support Hypothesis 3c) that there is a negative correlation between Health Literacy and Symptom Interference. A statistically significant weak negative correlation was found between Symptom Interference and Health Literacy $r = -.164$, $n= 211$, $p= .017$ showing that changes in Health Literacy scores are correlated with changes in Symptom Interference score in the opposite direction. As Health Literacy scores decrease, Symptom Interference scores increase. The correlation results do not support Hypothesis 3d) that there is a negative correlation between Health Literacy and Chemotherapy Self-Management. No significant correlation was found between Health Literacy and Chemotherapy Self-Management $r = -.076$, $n= 209$, $p= .275$. Since there was no significant relationship found between Health Literacy and Chemotherapy Self-Management, Health Literacy was not included in the regression model to explore the independent associations between Self-Efficacy, Symptom Severity and Symptom Interference and Chemotherapy Self-Management scores. In addition Symptom Interference was not statistically significantly associated with Chemotherapy Self-Management and as such, it was excluded from regression analyses that explored the independent associations between Self-Efficacy and Symptom Severity and Chemotherapy Self-Management score.
Table 18 Inter-Correlation and Descriptive Statistics Between Health Literacy, Self-Efficacy, Symptom Severity, Symptom Interference and Chemotherapy Self-Management

<table>
<thead>
<tr>
<th></th>
<th>Health literacy</th>
<th>Self-efficacy</th>
<th>Symptom severity</th>
<th>Symptom interference</th>
<th>Chemo self-management</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health literacy</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>32.77</td>
<td>5.87</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.03</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td>7.23</td>
<td>1.20</td>
</tr>
<tr>
<td>Symptom severity</td>
<td>-.14*</td>
<td>-.45**</td>
<td>1.00</td>
<td></td>
<td></td>
<td>1.91</td>
<td>1.36</td>
</tr>
<tr>
<td>Symptom interference</td>
<td>-.16*</td>
<td>-.46**</td>
<td>.51**</td>
<td>1.00</td>
<td></td>
<td>8.47</td>
<td>11.63</td>
</tr>
<tr>
<td>Chemo self-management</td>
<td>-.05</td>
<td>.21**</td>
<td>-.16*</td>
<td>-.09</td>
<td>1.00</td>
<td>.71</td>
<td>.14</td>
</tr>
</tbody>
</table>

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Note: Strength of Pearson correlation coefficient: 0 is no correlation, 1 is perfect positive, -1 perfect negative with -0.70 a strong negative, -0.50 moderate negative, -0.30 weak and the same on the positive side.

**Health Literacy and Health Service Utilization**

Kendall’s tau-b is a non-parametric alternative to Pearson correlation and is used when there are many tied ranks, which was the case with both the Health Literacy and Health Service Utilization data.

Prior to conducting Kendall’s tau-b, it was ensured that the assumptions for running this test were met: 1) the variables are measured on the ordinal or interval level and (here, all variables included in this analysis were measured on a continuous scale) and 2) there is a monotonic relationship between the variables.

The correlation results do not support Hypothesis 3e) that Health Literacy is negatively correlated with Health Service Utilization. Health Literacy level is independent of all four of the Health Service Utilization questions. There was no relationship found between Health Literacy and Number of Visits to a Healthcare Provider since the Start of Chemotherapy $r_{ul} = .009$, $p = .867$, between Health Literacy and Number of Visits to the Emergency Department since the Start of Chemotherapy $r_{ul} = .004$, $p = .949$, between Health Literacy and the Number of Hospitalizations since Start of Chemotherapy $r_{ul} = .077$, $p = .193$ and there was no relationship between Health Literacy and the Number of Nights Spent in Hospital since the Start of Chemotherapy $r_{ul} = .083$, $p = .148$. Since there were no significant relationships found between Health Literacy and any of the Health Service Utilization questions, Health Literacy was not included in the regression model.
to explore the independent contributions of the other independent variables on the Health Service Utilization questions.

**Correlations: Self-Efficacy, Symptom Severity, Symptom Interference, Chemotherapy Self-Management and the Four Items of Health Service Utilization**

Hypothesis 4: Self-Efficacy will be correlated with Symptom Severity, Symptom Interference and the dependent variables (Chemotherapy Self-Management and Health Service Utilization) in this sample, i.e., Self-Efficacy score is negatively correlated with Symptom Severity (Hypothesis 4a), Symptom Interference (Hypothesis 4b) and Health Service Utilization scores (Hypothesis 4c); Self-Efficacy score is positively correlated with Chemotherapy Self-Management score (Hypothesis 4d).

Pearson product-moment correlation coefficient analyses were used to explore correlations between continuous variables. The health service utilization questions did not meet the second assumption of Pearson correlation and as such, Kendall’s tau-b tests were conducted to explore the relationship between Health Service Utilization and Self-Efficacy.

Correlation results support Hypothesis 4a) that Self-Efficacy score is negatively correlated to Symptom Severity. Results from the Pearson correlation analysis showed that there was a statistically significant moderate, negative correlation found between Self-Efficacy and Symptom Severity with significance at the alpha = 0.01 level $r = -0.45$, $p < 0.01$. This showed that changes in Self-Efficacy score were associated with changes in Symptom Severity score in the opposite direction. As Self-Efficacy scores increase, Symptom Severity scores decrease. Correlation results also support Hypothesis 4b) that Self-Efficacy score is negatively correlated with Symptom Interference score. There was a significant moderate, negative correlation with significance at the alpha = 0.01 level between Self-Efficacy and Symptom Interference $r = -0.46$, $n = 211$, $p < 0.01$ meaning that as Self-Efficacy scores increase, Symptom Interference scores decrease. Correlation results also support Hypothesis 4c) that there is a positive correlation between Self-Efficacy and Chemotherapy Self-Management score. There was a statistically significant weak, positive correlation at the alpha = 0.01 level between Self-Efficacy and
Chemotherapy Self-Management \( r = .21, n = 209, p < 0.01 \) meaning that as Self-Efficacy score increases Chemotherapy Self-Management score increases.

Table 19 Inter-Correlation and Descriptive Statistics Between Self-Efficacy, Symptom Severity, Symptom Interference and Chemotherapy Self-Management

<table>
<thead>
<tr>
<th></th>
<th>Self-efficacy</th>
<th>Symptom severity</th>
<th>Symptom interference</th>
<th>Chemo self-management</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-efficacy</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom severity</td>
<td>-.45**</td>
<td>1.00</td>
<td></td>
<td></td>
<td>1.91</td>
<td>1.36</td>
</tr>
<tr>
<td>Symptom interference</td>
<td>-.46**</td>
<td>.51**</td>
<td>1.00</td>
<td></td>
<td>8.56</td>
<td>11.63</td>
</tr>
<tr>
<td>Chemo self-management</td>
<td>.21**</td>
<td>-.16*</td>
<td>-.09</td>
<td>1.00</td>
<td>.71</td>
<td>.14</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

**Self-Efficacy and Health Service Utilization**

Correlation results support Hypothesis 4d) that Self-Efficacy is negatively correlated to Health Service Utilization. Self-Efficacy score is correlated with all four of the health service utilization items. There is a weak negative correlation with statistical significance at the alpha = 0.01 level found between Self-Efficacy and Number of Visits to a Healthcare Provider Since the Start of Chemotherapy \( r_i = -.140, n=211, p=.006 \). This suggests that increases in Self-Efficacy score are associated with decreases in the Number of Visits to a Healthcare Provider Since the Start of Chemotherapy. There was a weak negative correlation with significance at the alpha = 0.01 level found between Self-Efficacy and Number of Visits to the Emergency Department Since the Start of Chemotherapy \( r_i = -.161, n=211, p=.002 \) which suggests that increases in Self-Efficacy score were correlated with decreases in the Number of Emergency Department Visits. There was also a weak negative correlation found between Self-Efficacy and Number of Times Hospitalized Since the Start of Chemotherapy \( r_i = -.132, n=211, p=.017 \) and a weak negative correlation found between Self-Efficacy and Number of Nights Spent in Hospital Since Start of Chemotherapy \( r_i = -.135, n=211, p=.012 \).

5.4 b) Multivariate Analysis

Although Health Literacy was excluded from regression analyses conducted to test the Hypotheses under Research Questions 3 and 4, additional analysis was conducted to test the independent association of variables that were significantly correlated with Health
Literacy score. A hierarchical multivariate regression analysis was conducted to explore whether the independent variables that were statistically significantly correlated with Health Literacy were associated with Health Literacy score in multivariate regression analysis.

**Contribution of Independent Variables to Explaining Variation in the Health Literacy Score**

A two-step hierarchical multivariate regression analysis was conducted with the Health Literacy score as the outcome variable. Only independent variables that were significantly correlated to the dependent variable in bivariate analysis were included (education level, country of birth, language spoken at home, income level, symptom severity and symptom interference). The socio-demographic variables (education, country of birth, language spoken at home, and income level) were entered as Block 1 and the disease related variables (symptom severity and symptom interference) were entered as Block 2.

The hierarchical multivariate regression analysis revealed that the socio-demographic variables comprising Block 1 accounted for 20% of the variation in Health Literacy score with a statistically significant contribution ($R^2 = .203, (F(4,144)=9.192, p <0.001)$. Introducing Symptom Severity and Symptom Interference were entered at Block 2 and explained an additional 2.2% of variance in Health Literacy score and the change in $R^2$ was significant ($R^2 = .225, (F(2,142)=1.993, p <0.001)$. When all independent variables were included in the final HLR Model, Education ($\beta = 2.815, p = .001$, 95% CI [1.232, 4.398]) and Language Spoken at Home ($\beta = -4.746, p <0.001$, 95% CI [-7.309, -2.184]) were significant predictors of Health Literacy score. The results showed that participants with higher Education Levels had higher Health Literacy scores and those who spoke a language other than English at home had lower Health Literacy scores.

Table 14 presents the results of the hierarchical multivariate regression model that explored the contribution of independent variables to Health Literacy as an outcome variable.
Table 20 Hierarchical Multivariate Regression Model: Contribution of Independent Variables to Health Literacy

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
<th>p</th>
<th>R²</th>
<th>ΔR²</th>
<th>ΔF</th>
<th>pΔF</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Block 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education level</td>
<td>2.919</td>
<td>.803</td>
<td>.277</td>
<td>3.635</td>
<td>.001***</td>
<td>.203</td>
<td>.181</td>
<td>9.192***</td>
<td>.001</td>
</tr>
<tr>
<td>Country of birth</td>
<td>-7.38</td>
<td>.923</td>
<td>-0.064</td>
<td>-7.799</td>
<td>.426</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language spoken at home</td>
<td>-4.615</td>
<td>1.300</td>
<td>-0.287</td>
<td>-3.549</td>
<td>.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income level</td>
<td>.326</td>
<td>.297</td>
<td>.084</td>
<td>1.099</td>
<td>.274</td>
<td></td>
<td></td>
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<tr>
<td><strong>Block 2</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education level</td>
<td>2.815</td>
<td>.801</td>
<td>.267</td>
<td>3.515</td>
<td>.001***</td>
<td>.225</td>
<td>.192</td>
<td>1.993***</td>
<td>.140</td>
</tr>
<tr>
<td>Country of birth</td>
<td>-.504</td>
<td>.925</td>
<td>-0.044</td>
<td>-0.545</td>
<td>.586</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language spoken at home</td>
<td>-4.746</td>
<td>1.296</td>
<td>-0.296</td>
<td>-3.662</td>
<td>.001***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income level</td>
<td>.297</td>
<td>.297</td>
<td>.077</td>
<td>.999</td>
<td>.320</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom severity</td>
<td>-.260</td>
<td>.364</td>
<td>-0.062</td>
<td>-.713</td>
<td>.477</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom interference</td>
<td>-.054</td>
<td>.043</td>
<td>-.108</td>
<td>-1.245</td>
<td>.215</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p<0.05, **p<0.01, ***p<0.001

5.5 Section 3: Hierarchical Linear Multiple Regression Models

Health Literacy was not significantly correlated with any of the dependent variables in univariate and multivariate analysis (chemotherapy self-management, number of visits to a healthcare provider since start of chemotherapy, number of visits to the emergency department since the start of chemotherapy, number of hospitalizations since the start of chemotherapy and number of nights spent in hospital since the start of chemotherapy). As such, it was not included as an independent variable in the hierarchical multivariate regression analyses. Research Questions 3 and 4 were modified accordingly and explore the association of Self-Efficacy on outcomes in place of Health Literacy.

Prior to conducting hierarchical linear multiple regression (HLR) analysis the assumptions for fitting an HLR model were tested. These assumptions are: 1) all dependent variables are measured on a continuous scale, 2) more than two independent variables are included in the model, 3) residual and scatterplots were used to determine whether there were linear relationships between the dependent variable and each independent variable, and 4) homogeneity of variance is tested. All assumptions were met [217]. Prior to entry of variables in HLR models, multiple linear regression analyses were used to examine multicollinearity among variables (i.e., socio-demographic and cancer-related variables). To do this, each independent variable was included as the dependent variable in individual models. Results showed non-significant multicollinearity between independent variables with the Variance Inflation Factor (VIF) at just over 1 between all variables [211]. Only independent variables that were statistically
significantly correlated with dependent variables were entered in the HLR Models and these were entered in order of statistical significance [211].

For each hierarchical multivariate regression analysis, the blocks in which independent variables were entered into the analysis were guided by the adapted conceptual framework based on Paasche-Orlow & Wolf’s causal model [130]. As such, socio-demographic variables (where applicable) were entered first, followed by the disease variables and then the independent variables.

5.5 a) Self-Efficacy and Chemotherapy Self-Management Behaviours

Research Question 3: Is Self-Efficacy associated with Chemotherapy Self-Management score independent of Symptom Severity and Symptom Interference?

**Hypothesis 5:** Self-Efficacy contributes independently and significantly to explaining the variation in Chemotherapy Self-Management score.

**Association of Self-Efficacy to Chemotherapy Self-Management Behaviours (Model 1)**

A three-step hierarchical multivariate regression analysis was conducted with Chemotherapy Self-Management score as the dependent variable. The socio-demographic variables that were significantly correlated to Chemotherapy Self-Management score that is, Country of Birth and Language Spoken at Home were entered as Block1, Symptom Severity was entered as Block 2 and Self-Efficacy as Block 3.

The regression results support Hypothesis 5, Self-Efficacy is associated with Chemotherapy Self-Management score. The hierarchical multivariate regression analysis revealed that at Block 1, Language Spoken at Home and Country of Birth accounted for 5% of the variation in Chemotherapy Self-Management score and this was a statistically significant contribution ($R^2 = .049, (F(2, 203)=5.212, p=.006)$. Introducing Symptom Severity at Block 2 explained an additional 3% of variation in Chemotherapy Self-Management score and this change in $R^2$ was significant ($R^2 = .080, (F(1, 202)=6.784, p=.010)$. Adding Self-Efficacy to the regression model at Block 3 explained an additional 3% of variation in the Chemotherapy Self-Management score and this change in $R^2$ was significant ($R^2 = .105, (F(1, 201)=5.716, p=.018)$. When all independent variables were included in the final HLR model, Country of Birth ($\beta = .045, p=.028$,
95% CI [.005, .086]) and Self-Efficacy (β= .021, p= .018, 95% CI [.004, .038]) were significant predictors of Chemotherapy Self-Management score. The results showed that participants, who were born in Canada and those who had higher Self-Efficacy, had higher Chemotherapy Self-Management scores. Together, all independent variables accounted for 11% of variance in Chemotherapy Self-Management score. Table 15 presents the results of five hierarchical multivariate regression models that explored the contribution of Self-Efficacy on outcomes.

5.5 b) Self-Efficacy and Health Service Utilization

Research Question 4: Is Self-Efficacy score associated with Health Service Utilization independent of the variables considered in research question 3 and Chemotherapy Self-management score.

**Hypothesis 6:** Self-Efficacy contributes independently and significantly to explaining the variation in Health Service Utilization scores.

**Association of Self-Efficacy to Health Services Utilization – Visits to Healthcare Provider Since Start of Chemotherapy (Model 2)**

A two-step hierarchical multivariate regression analysis was conducted with number of visits to a healthcare provider since the start of chemotherapy as the dependent variable. Only independent variables that were significantly correlated with the dependent variable in bivariate analysis were entered (symptom severity, symptom interference and self-efficacy,). Symptom Severity and Symptom Interference were entered as Block 1 and Self-efficacy was entered as Block 2.

The regression results did not support Hypothesis 6) that Self-Efficacy would contribute variation to the Health Service Utilization variables. Self-Efficacy did not independently contribute to variation in the number of Visits to Healthcare Provider Since Start of Chemotherapy. The hierarchical multivariate regression analysis revealed that at Block 1, Symptom Severity and Symptom Interference accounted for 8.6% of the variation in number of visits to a healthcare provider since the start of chemotherapy, with a statistically significant contribution ($R^2 = .086, (F(2, 207) = 9.690, p < 0.001$). Introducing Self-Efficacy at Block 2 explained an additional .2% of variation in number of visits to a healthcare provider and this change in $R^2$ was significant ($R^2 = .087, (F(1, 206) = .341, p < 0.001$). When all independent variables were included in the final HLR
Model, Symptom Interference ($\beta = .256, p = .002, 95\% \text{ CI } [.003, .014]$) was the only significant predictor of number of visits to a healthcare provider. Together, all independent variables accounted for 8.7% of variance in number of visits to a healthcare provider since the start of chemotherapy. The results showed that participants with higher symptom interference scores had higher numbers of visits to a healthcare provider since the start of chemotherapy.

**Association of Self-Efficacy to Health Services Utilization – Visits to the Emergency Department Since Start of Chemotherapy (Model 3)**

A three-step hierarchical multivariate regression analysis was conducted with number of visits to the emergency department since the start of chemotherapy as the outcome variable. Only independent variables that were significantly correlated to the dependent variable in bivariate analysis were entered (country of birth, symptom severity, symptom interference, and self-efficacy). Country of Birth was entered as Block 1, Symptom Severity and Symptom Interference was entered as Block 2, and Self-Efficacy was entered as Block 3.

The regression results do not support the Hypothesis that Self-Efficacy would independently contribute to variation in the number of Visits to the Emergency Department Since Start of Chemotherapy. The hierarchical multivariate regression analysis revealed that at Block 1, Country of Birth accounted for 2.1% of the variation in number of visits to the emergency department since the start of chemotherapy, with a statistically significant contribution ($R^2 = .021, (F(1, 206) = 4.489, p = .035$). Introducing Symptom Severity and Symptom Interference at Block 2 explained an additional 3.9% of variation in number of visits to the emergency department and this change in $R^2$ was significant ($R^2 = .060, (F(2, 204) = 4.212, p = .016$). Adding Self-Efficacy to the regression model at Block 3 explained an additional 1.3% of variation in number of visits to the emergency department since the start of chemotherapy and this change in $R^2$ was not significant ($R^2 = .073, (F(1, 203) = 2.834, p = .094$). When all independent variables were included in the final HLR Model, none of the variables contributed to the model. Together, all independent variables accounted for 7.3% of variance in number of visits to the emergency department since the start of chemotherapy.
**Association of Self-Efficacy to Health Services Utilization – Hospitalizations Since Start of Chemotherapy (Model 4)**

A two-step hierarchical multivariate regression analysis was conducted with number of hospitalizations since the start of chemotherapy as the outcome variable. Only independent variables that were significantly correlated to the dependent variable in bivariate analysis were included (symptom interference and self-efficacy). Symptom Interference was entered as Block 1 and Self-Efficacy was entered as Block 2.

The regression results do not support the Hypothesis that Self-Efficacy independently contributes to variation in the number of Hospitalizations Since Start of Chemotherapy. The hierarchical multivariate regression analysis revealed that at Block 1, Symptom Interference accounted for 3.6% of the variation in number of hospitalizations since the start of chemotherapy, with a statistically significant contribution ($R^2 = .036$, $(F(1, 209) = 7.720, p = .006$). Introducing Self-Efficacy at Block 2 explained a very small additional .5% of variation in number of hospitalizations and this change in $R^2$ was not significant ($R^2 = .041$, $(F(2, 208) = 1.115, p = .292$). When all independent variables were included in the final HLR Model, Symptom Interference ($\beta = .002$, $p = .050$, 95% CI [.000, .005]) was the only significant predictor of number of hospitalizations. Together, all independent variables accounted for 4.1% of variance in number of hospitalizations since the start of chemotherapy. The results showed that participants with higher symptom interference scores had higher numbers of hospitalizations since the start of chemotherapy.

**Association of Self-Efficacy to Health Services Utilization – Number of Nights Spent in Hospital Since Start of Chemotherapy (Model 5)**

A two-step hierarchical multivariate regression analysis was conducted with number of nights spent in hospital since the start of chemotherapy as the outcome variable. Only independent variables that were significantly correlated to the dependent variable in bivariate analysis were included (symptom interference and self-efficacy). Symptom Interference was entered as Block 1 and Self-Efficacy was entered as Block 2.

The regression results do not support the Hypothesis that Self-Efficacy independently contributes to variation in the number Nights Spent in Hospital Since Start of Chemotherapy. The hierarchical multivariate regression analysis revealed that at Block 1,
Symptom Interference accounted for a small variation in number of nights spent in the hospital since the start of chemotherapy 2.3%, with a statistically significant contribution ($R^2 = .023, (F(1, 209) = 4.992, p = .027)$. Introducing Self-Efficacy at Block 2 explained an additional 1.2% of variation in number of nights spent in the hospital and this change in $R^2$ was not significant ($R^2 = .035, (F(1, 208) = 2.520, p = .114)$. When all independent variables were included in the final HLR Model, none were significant predictors of number of nights spent in the hospital since the start of chemotherapy. Together, all independent variables accounted for 3.5% of variance in number of nights spent in hospital since the start of chemotherapy.
### Table 21 Hierarchical Multivariate Regression: Contribution of Self-Efficacy to Chemotherapy Self-Management Behaviours and Health Service Utilization

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### Model 2. Contribution of self-efficacy to health service utilization: visits to healthcare provider since start of chemotherapy

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### Model 3. Contribution of self-efficacy to health service utilization: visits to emergency department since start of chemotherapy

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### Model 4. Contribution of self-efficacy to health service utilization: number of hospitalizations since start of chemotherapy

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### Model 5. Contribution of self-efficacy to health service utilization: number of nights spent in hospital since start of chemotherapy

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5.6 Section 4: Summary of Results

Health Literacy was not significantly correlated with any of the dependent variables in univariate and multivariate analysis (chemotherapy self-management, number of visits to a healthcare provider since start of chemotherapy, number of visits to the emergency department since the start of chemotherapy, number of hospitalizations since the start of chemotherapy and number of nights spent in hospital since the start of chemotherapy). As such, Health Literacy was not included as an independent variable in any of the hierarchical multivariate regression analyses that focused on the dependent variables mentioned above. However, a hierarchical multivariate regression analysis was conducted to explore whether the independent variables that were statistically significantly correlated with Health Literacy were also associated with Health Literacy score in hierarchical multivariate regression analysis. The results showed that the socio-demographic variables, Education Level and Language Spoken at Home, explained a significant amount of variance (22.5%) in Health Literacy score. Participants with higher Education Levels had higher Health Literacy scores and participants that Spoke a Language at Home that was not English had lower Health Literacy scores.

The results of the hierarchical multivariate regression analyses that was conducted to explore the association of Self-Efficacy to the Chemotherapy Self-Management score and the four Health Service Utilization variables (number of visits to a healthcare provider, number of visits to the emergency department, number of hospitalizations, and number of nights spent in hospital), showed that Self-Efficacy contributed to explaining variation in the Chemotherapy Self-Management score but did not contribute significantly to explaining Health Service Utilization. The additional variable that contributed to explaining variation in Chemotherapy Self-Management score was Country of Birth. Participants who were born in Canada had higher Chemotherapy Self-Management scores than their counterparts born outside of Canada.

With regard to the measures of Health Service Utilization, only the variable, Symptom Interference, contributed to explaining statistically significant variation in Number of Visits to a Healthcare Provider Since the Start of Chemotherapy and also to the Number of Hospitalizations Since the Start of Chemotherapy.
Chapter 6: Discussion

This study advances knowledge with regard to the association of health literacy and self-efficacy on chemotherapy self-management behaviours and health service utilization in the context of cancer care. The socio-demographic variables that are associated with health literacy were mostly consistent with the adapted Paashe-Orlow and Wolf conceptual framework that was used to guide this study. However, contrary to evidence in the chronic disease self-management literature that underpinned the adapted model, health literacy was not associated with chemotherapy self-management behaviours nor was it associated with health service utilization. Moreover, health literacy was not associated with self-efficacy. Self-efficacy, however, and country of birth were associated with chemotherapy self-management while health service utilization was not. These findings are discussed below in detail and the implications for research, health policy, and practice are highlighted in the Conclusion Chapter.

6.1 Health Literacy and Cancer Patients Receiving Chemotherapy

The majority of patients in the sample of study participants scored high on the health literacy measure (S-TOFHLA). This indicates that most participants in the study had adequate health literacy. This was an unexpected finding. Others have found that the prevalence of inadequate health literacy in Canada is high with estimates that 60% of adult Canadians have low health literacy and that 88% of Canadian seniors have low health literacy [4, 218]. Since cancer is a disease that disproportionately affects individuals that are 50 years of age and older, Hypothesis #1 was that, among cancer patients at Princess Margaret Cancer Centre (PM) receiving chemotherapy, a majority of participants would have inadequate health literacy. There are three factors that may help explain this result: 1) individuals with inadequate health literacy are not receiving chemotherapy at the same rate as individuals that have adequate health literacy; 2) individuals with inadequate health literacy are less likely to participate in survey research; 3) the measure of health literacy used (S-TOFHLA) does not precisely capture the desired construct of health literacy.
It is well known that inadequate health literacy is associated with underutilization of preventative health services including cancer screening [95, 96, 142, 156, 158-160, 163]. This is in part, explained by the association of inadequate health literacy and important health-related decision-making skills. For example, inadequate health literacy is associated with poor use of comparative health information [56, 165] and poor knowledge and beliefs about disease [17, 41, 54, 56, 59, 91, 92, 96, 139-142]. Knowledge and beliefs can influence patient behaviours in terms of identifying potential problems and taking appropriate actions including seeking health services and communicating with healthcare providers [92, 219, 220]. For example, inadequate health literacy is associated with less uptake of cancer screening practices including Pap test (OR .06, CI: 0.1, .55) [95]; (OR .1.7, CI 1.0, 3.1) [3]; (B=.05 (.02); p<.05) [221], mammography (B=.2 (.04); p<.05) [221], colorectal cancer screening (RR =.56, CI: .38, .83) [96], and sunscreen use (OR .85, CI: .81, .89) [222]. In other chronic diseases, inadequate health literacy is associated with underutilization of health services including kidney transplantation and visits to primary care physicians [157, 162].

Less is known about the association of health literacy to health behaviours in acute cancer care however the same barriers to uptake of preventative cancer care, poor use of comparative health information and poor knowledge and beliefs about disease, could apply to the acute cancer treatment setting. A recent study published in the journal of Cancer Control found that adequate health literacy increases the chance of receiving chemotherapy among patients with Stage III or IV disease (OR 3.29, CI: 1.23, 8.80) [223]. The reasons for this were not provided in the study, however the implication is that health literacy related factors play a role and these are discussed below. Another study found that refusal of curative radiation therapy and surgery was prevalent among cancer patients with the socio-demographic predictors of inadequate health literacy (e.g. advancing age, low income, new immigrant status) [221]. The results of both of these studies that show underutilization of cancer treatments could be explained by a number of health literacy related factors, such as poor reading ability, that have been associated with difficulty accessing the healthcare system, understanding recommended treatments and their benefit, and following instructions from healthcare providers [224].
If these findings were applicable to acute cancer care at PM, it could mean that a significant number of patients with inadequate health literacy were not represented among those eligible to participate in this study. It could help to understand why the majority of participants in this sample scored high on the measure of health literacy and could point to a significant challenge to health services researchers studying health literacy in cancer. It could also indicate significant health policy and practice issues where cancer care is not accessed equitably. Nutbeam’s conceptualization of health literacy that was discussed in the introduction to this work, holds that improving health literacy at the population level involves multiple efforts that include acknowledgement and understanding of the political aspects to education, focused on overcoming structural barriers to health.

From the perspective of access to health care, the cancer treatment system is fraught with complexity [225, 226] and as such, individuals with inadequate health literacy may have greater difficulty accessing cancer services [221, 223]. The Paasche-Orlow and Wolf model articulates this complexity and shows how health literacy can impact health outcomes at three points in the continuum of care [130]. These factors are: Access and Use of Health Care, Provider-Patient Interactions, and Patient Self-Care [130]. At each of these three points of care, Paasche-Orlow and Wolf explore factors that could moderate or mediate the relationship between patient health literacy and outcomes (see Figure 1) [130]. These factors are: System factors (e.g., complexity, acute care orientation, tiered delivery system); Provider factors (e.g., communication skills, teaching ability, time, patient-centred care); Patient factors (e.g., navigation skills, self-efficacy, knowledge, motivation); and Extrinsic factors (e.g., support technologies, mass media, health education, resources) [130]. This dissertation research focused on patient self-care competencies only and did not account for System, Provider or Extrinsic factors including the complexity of health systems and the communication skills of providers. Attention should be paid to the effect of system complexity on access and utilization in future studies [227].

Attention should also be given to the impact of provider communication skills on patient access to the cancer treatment system. The literature shows that inadequate health literacy
impairs communication and discussion about risks and benefits of treatment options, and patient understanding of informed consent for routine procedures as well as clinical trials [133]. This can have an effect on patient access to health services. The literature also shows that patients often do not understand the purpose of routine screening, the meaning of important medical terms like ‘tumour’ or ‘malignancy’ [133], and this can impact patient perception of illness and motivation for care [8, 133]. The Institute of Medicine and several health literacy leaders recommend that providers receive plain language communication training to mitigate the risks of inadequate health literacy [8, 228].

The Paasche-Orlow and Wolf model for the causal pathway from health literacy to health outcomes provides a useful framework for health literacy research. Further research in health literacy and cancer should account for Access and Use of Health Care, Provider-Patient Interactions, and Patient Self-Care in study designs.

Another factor that could shed some light on the highly skewed health literacy scores is the challenge of recruiting large numbers of people with inadequate health literacy to participate in research. Patients with inadequate health literacy are more likely to elect not to participate in healthcare decision-making [229, 230] and in research [231] which can result in selection bias. This is likely due to the high order health literacy skills that are required to participate in these activities [231]. This includes reading consent forms, completing measures and surveys, as well understanding the purpose of the research and what participation entails [231]. In addition, individuals with inadequate health literacy may have distrust in the research enterprise [231] and experience shame at disclosing challenges with reading [200]. A systematic review of strategies to reach socially disadvantaged groups to participate in health research suggests that one method to encourage participation among individuals with inadequate literacy is to use plain language in self-administered surveys [232-234]. The same systematic review also suggests that self-administered surveys should be avoided for low literacy groups and that interviews could be used as an alternative [232]. These recommendations were followed for data collection in this dissertation research. The invitation to participate in the study script was written in plain language and the parts of the questionnaire that were not comprised of validated instruments (socio-demographic section and cancer
characteristics), were written in plain language. The questionnaire package was read aloud to participants to avoid the necessity for reading skills however participants were required to complete the Short-Test of Functional Health Literacy (S-TOFHLA) independently. This requirement may have discouraged individuals with inadequate health literacy from participating in the research. In future, the possibility of improving participation from those with inadequate health literacy could be addressed through use of an oral measure of health literacy such as the Rapid Estimate of Adult Literacy in Medicine (REALM) [235].

A further consideration to improve participation rates of individuals with inadequate health literacy in future research is to avoid English fluency as an inclusion criteria. A recent study that was conducted among women whose second language was English showed that individuals could score adequate health literacy in their first language, and score inadequate health literacy in English [205]. This implies that individuals who may be highly health literate in their first-language may not be highly health literate in English. As such, individuals with limited English fluency are at risk of having inadequate health literacy within an English language health care system. An inclusion criterion for this dissertation study was that participants were sufficiently fluent in English to complete the study questionnaire package. Recall that in the study sample, speaking a language at home other than English is associated with lower health literacy scores. Had English fluency not been a requirement of participation, it is possible that a greater number of individuals with inadequate health literacy would have participated.

Although the Test of Functional Health Literacy (TOFHLA) and its short form, the Short-Test of Functional Health Literacy (S-TOFHLA), have been used in multiple studies, and continue to be considered among the gold standards in health literacy measurement, they have been criticized for only measuring reading comprehension which comprises only part of the concept of health literacy [219, 223, 236]. Several studies that have utilized the S-TOFHLA in samples of cancer patients and others have also obtained samples with low percentages of participants with marginal or inadequate health literacy [220, 237, 238]. This may be explained in part, by the S-TOFHLA being an incomplete measure of health literacy. The measurement of health literacy has received much attention by health
literacy researchers over the last decade [106, 239]. The challenge is that many of the dimensions of health literacy are difficult to quantify [239]. These parts include health system level barriers, health care provider communication skills, as well as an individual’s oral literacy and numeracy [106]. Sorenson and Osborne have developed measures of health literacy that are intended to capture system level and provider communication barriers (HLS-EU-Q and HLQ) [111, 117]. It is possible that had the HLS-EU-Q or the HLQ been utilized in this research, a different or more nuanced result would have been found. In addition, some health literacy researchers have advocated for disease specific measures of health literacy, including cancer health literacy [114, 115, 240]. Proponents of this approach argue that the skills required of cancer patients are sufficiently complex to warrant a separate conceptualization [114, 115, 240].

The low numbers of participants with marginal or inadequate health literacy in this study could be related to any of the factors discussed above or could be compounded by all three. Individuals with inadequate health literacy may not be as represented in the cancer treatment system as their counterparts with adequate health literacy; those that are present may be less likely to participate in research, and perhaps those that participate in research have higher English reading comprehension scores than those who refuse; and the most commonly used measures of health literacy are only assessing reading level in the context of health. These are important considerations for health policy, practice and research and are summarized in the Conclusion.

6.2 Health Literacy and Socio-Demographic Characteristics

Based on the extant literature, it was hypothesized that the socio-demographic variables that are known to be associated with health literacy would also be associated with health literacy in this sample. The literature shows that older age is associated with lower health literacy scores [119, 121, 141, 220, 237]; higher levels of education are associated with high health literacy scores [26, 130]; country of birth is associated with health literacy score in that, participants born outside of country of residence have lower health literacy scores than participants born in their country of residence [26, 130]; language spoken at home is associated with health literacy score in that, participants that speak the primary language of residence at home have higher health literacy scores than participants who
speak languages other than the primary language of residence at home [26, 130]; and participants with higher income levels have higher health literacy scores [26, 130]. All of these associations were observed in this study with the exception of age. This result was unexpected, and may be explained by differences in the characteristics of this study’s elderly participants relative to those in prior studies. Being elderly is known to be negatively associated with health literacy, with individuals older than 65 years of age having lower health literacy [119, 121, 141, 220, 237]. In studies that report an association between age and health literacy, elderly participants are also found to have lower levels of education attainment (below high school) [237, 241]. In this sample, a high proportion of elderly participants had levels of education that were above high school (73/79). This may in part, explain why age is not associated with health literacy score in the sample. Further explanation may be provided through an examination of the other relevant socio-demographic characteristics of participants. Among the elderly participants in this study, the vast majority spoke English at home (70/79). Country of birth may have an effect as well since the majority of elderly participants were born in Canada (46/79). With regard to income level, the majority of elderly participants that responded to the income question indicated that they earn greater than 50,000 K/ per year (37/55). In addition, as mentioned above, it is possible that individuals with inadequate health literacy are not accessing cancer treatment at the same rate as patients with adequate health literacy. Thus, the composition of the sample in this study may reflect an unintended selection bias toward patients with adequate health literacy receiving cancer care.

6.3 Health Literacy and Self-Efficacy

No association between health literacy and self-efficacy was found, and this is not an entirely unexpected finding. Findings in the extant literature are mixed with some studies showing an association between health literacy and self-efficacy [52, 57, 92, 150], whereas others show no association [146, 152]. Albert Bandura, in his definition of self-efficacy, embedded the idea that individuals make use of their efficacy judgments in reference to some goal which reflects both the task and situation-specific nature of self-efficacy beliefs [242]. In other words, there is no one-size fits all measure of self-efficacy
Self-efficacy is context specific and as such, some types of self-efficacy are associated with health literacy and some are not. Whether health literacy is associated with self-efficacy will thus depend on the specific measure of self-efficacy used in the studies. To date, no other studies have explored the association between health literacy and cancer coping self-efficacy and as such, this study contributes to the literature.

Most of the published literature that explores the link between health literacy and self-efficacy has found positive associations between self-efficacy and health literacy [52, 57, 92, 150] with higher levels of health literacy being associated with higher levels of self-efficacy. For example, one study examined the association between health literacy and self-efficacy for diabetes self-care and, in multivariate analysis, health literacy was positively associated with self-efficacy for diabetes self-care while controlling for patient and clinical characteristics [57]. Another study examined the influence of health literacy on self-efficacy for colorectal cancer screening and they found that high health literacy was associated with high self-efficacy for participating in colorectal cancer screening [92]. Both studies explored a type of cancer-related self-efficacy and measured health literacy using the Test of Functional Health Literacy in Adults (TOFHLA) and had a similar sample size and similar mean age of participants. The findings from this earlier study support Bandura’s definition of self-efficacy and the focus on specific tasks and contexts.

6.4 Health Literacy and Symptoms

Associations were found in this study between health literacy and symptom severity as well as symptom interference. As health literacy scores decreased, symptom severity and symptom interference scores increased. The literature shows that inadequate health literacy is associated with poorer health status [3, 17, 244, 245] and increased hospitalizations [246, 247]. As such, these results could suggest that individuals with inadequate health literacy may be less equipped to identify potentially problematic symptoms in a timely way, and subsequently, the symptoms become more burdensome.
6.5 Health Literacy and Chemotherapy Self-Management

No association was found between health literacy and chemotherapy self-management. This was an unexpected finding since there is a large body of evidence for associations between health literacy and several self-management behaviours in other chronic diseases [23, 77, 147, 150]. The evidence for associations between health literacy and self-management in the cancer context however, is sparse and is largely confined to the domain of preventative cancer behaviours. This may be explained in part by the fact that self-management is a relatively new concept in cancer. As such, few instruments have been developed to measure cancer self-management behaviours. The instrument used to measure chemotherapy self-management behaviours was the only cancer specific measure of self-management behaviours identified in the acute phase of cancer care that had good internal consistency reliability [79]. A measure has now been developed to measure cancer self-management behaviours however it is primarily focused on self-efficacy [248].

As mentioned, the published cancer self-management literature is focused on preventative self-management behaviours that are largely measured using health services data (i.e., uptake of mammography, pap tests) rather than collected by self-report survey instrument. This may contribute to an explanation as to why this area of research is in its infancy despite the compelling evidence of its importance in the chronic disease literature. A recent study explored whether patient confidence to manage the side effects of oral oncolytic agents was associated with health literacy and found that individuals with adequate health literacy had higher confidence to manage the side effects [173]. Although important, this study did not utilize a validated measure of health literacy nor did they use a validated measure of side effect management. This is likely because only very few adequate measures of cancer self-management behaviours exist. This will be a challenge in the field of cancer self-management until measures are developed and validated.
6.6 Health Literacy and Health Service Utilization

There was also no association found between health literacy and any of the measures of health service utilization. These findings were unexpected since there is ample evidence in the chronic disease literature of strong associations between health literacy and utilization of health services [3, 15, 17, 244-247]. Several of these studies measured health literacy using the same instrument that was used in this dissertation research, the Short Test of Functional Health Literacy in Adults (S-TOFHLA) [3, 15] and the measures of health service utilization ranged from self-administered survey to collection of data from clinical records.

Since health literacy was not found to be associated with the main dependent variables in the study, it was excluded from regression analysis. However, since self-efficacy is associated with both chemotherapy self-management and some of the measures of health service utilization, it was further explored in regression analysis.

6.7 Self-Efficacy and Chemotherapy Self-Management

Self-efficacy was significantly positively associated with participant’s chemotherapy self-management scores: higher self-efficacy scores are associated with higher chemotherapy self-management scores. This is an important finding because despite the fact that self-efficacy has been accepted as an important predictor of self-management behaviours in other chronic diseases, (i.e. chronic kidney disease, diabetes, cardiovascular disease), little has been published in cancer [249-251]. The few studies that have been published in cancer report that self-efficacy is associated with important self-management behaviours [246, 252]. A recent study provided evidence for the association of self-efficacy on cancer patient ability to self-manage care in the year following primary treatment [253]. The study found that patients with low self-efficacy scores were more likely to report higher pain levels, higher depression scores, and lower inner-well-being scores [253]. Another study found that perceived self-efficacy had a positive effect on the physical functional status of cancer patients while serving as a mediator between cancer related fatigue severity and physical functional status [254]. A possible explanation as to why there are few published studies to support the association of self-efficacy on cancer self-
management behaviours is that few measures of cancer self-management behaviours have been developed to date.

6.8 Self-Efficacy and Health Service Utilization

Self-efficacy is not associated with health service utilization and this is not an entirely unexpected finding. There is some evidence in the published literature that self-efficacy is associated with health service utilization, and the direction of the association seems to be dependent on the specific health service. For example, self-efficacy is associated with treatment utilization where patients with lower self-efficacy are less likely to undergo treatments compared to those with higher self-efficacy [255]. Another study showed that lower self-efficacy was associated with decreased use in emergency departments among a population of underserved men with prostate cancer [256]. A study conducted with asthma patients showed that higher self-efficacy was associated with fewer hospitalizations [257]. In each of these studies, it is challenging to understand whether self-efficacy was a help or hindrance because they did not include an appraisal of whether utilization of the health services was appropriate at the patient level. It is well known that strategies to increase self-efficacy among patients can improve appropriate health service utilization [255]. More research is needed to explore the association of health literacy on various health services and these should include an appraisal of whether the behaviours undertaken were appropriate.

6.9 Strengths and Limitations

The limitations of this study are related to study design, sample, and threats to validity. The cross-sectional design provides participant responses at one point in time and limits applicability outside of the study setting. With regard to collecting responses at one point in time, cancer coping self-efficacy can change over time related to patient circumstances [206]. It would be interesting to study whether self-efficacy would continue to have the same association with chemotherapy self-management behaviours over time or if it would differ. Another limitation to acknowledge is the potential for type I errors (falsely rejecting a null hypothesis) or type II errors (falsely accepting a null hypothesis).
In addition, the convenience sample limits the generalizability of study findings (selection bias) and also limits inference making about the entire population. This subsequently lends low external validity to the study. On the other hand, the preliminary nature of this study provides important quantitative data and learning for hypothesis generation for future prospective studies. This study is among the largest studies conducted in this area to date.

There are limitations with regard to the scoping review that was conducted to explore the relationship between health literacy and self-management behaviours in the chronic disease literature. First, the search strategy included only one of several known databases for clinical literature (OVID Medline). Second, the review reflected articles published only up until 2013. As such, it is very possible that relevant studies were not included in the literature summary.

The majority of participants in this study had high levels of health literacy. This could be a result of non-response sample bias where the method of data collection used unintentionally biased individuals with inadequate health literacy to decline participation in the study. Although efforts were made to mitigate this possibility by administering the questionnaire package orally, participants were still required to complete the measure of health literacy independently. For individuals with inadequate health literacy, this could prevent them from wishing to participate out of fear of discovery or shame [200]. In future, this could be avoided by utilizing a measure of health literacy that is also administered orally such as the Rapid Estimate of Adult Literacy in Medicine (REALM) [235]. In addition, English fluency was an inclusion criterion that may have unintentionally served to exclude individuals with inadequate health literacy from participating in the study. As mentioned above, English as a second language puts individuals at higher risk of inadequate health literacy than their first language English speaking counterparts, when in an English dominant health care setting [26].

An important potential further limitation to this dissertation research is selection bias of another type. Selection bias may be present since some literature reports that individuals with inadequate health literacy may not be represented in the cancer treatment system to
the same degree as their adequate health literacy counterparts [221, 223]. This could present serious challenges to studying the association between health literacy and acute cancer self-management behaviours.

Health literacy was not associated with participant age in this sample. This could be due to the fact that in this sample, older participants were more highly educated and had higher incomes than their age counterparts in studies that show age over 65 years associated with health literacy [237, 241].

Although this dissertation research was focused on health literacy, the measure of health literacy that was utilized only measured functional health literacy. Although this measure is considered a gold standard in health literacy research, it does not sufficiently measure the complexity of health literacy. As such, the prevalence of inadequate health literacy may be understated due to measurement bias. Future research should include a more complete measure of health literacy [106].

Another consideration is the measure of self-efficacy that was selected. As discussed above, in some studies health literacy is associated with some types of self-efficacy and not associated with others. There was no association found between health literacy and cancer coping self-efficacy in this study however, future research could include multiple measures of relevant cancer self-efficacy types to assess the relationship using multiple measures.
Chapter 7: Conclusion and Implications

The importance of health literacy to equitable and optimal health care provision is demonstrated in the chronic disease literature and although health literacy principles apply in the cancer care system, there is a dearth of evidence for its importance in the cancer literature.

7.1 Implications for Policy

Recent studies have shown that cancer patients with inadequate health literacy are not accessing and utilizing relevant health services at the same rate as their adequate health literate counterparts and this impacts their outcomes [221, 223]. The reasons for this are multifactorial and include: the complexity of the cancer system and the high order health literacy skills that are needed to navigate it; communication challenges between patients and healthcare providers; and the knowledge and skills of patients themselves. If health literacy is not measured at a systems level, it will be difficult to account for it in developing strategies to advance equitable cancer care and this would be an unfortunate consequence. Baseline data is needed in order for progress to be seen and this cannot be gathered without meaningful measures.

Prominent health organizations promote the importance of health literacy at the international, national and local level. These organizations include the World Health Organization [258], the Institute of Medicine [8], the Agency for Healthcare Research and Quality [259], the Canadian Medical Association and the Canadian Nurses Association [260], the Public Health Agency of Canada [261], the Ontario Public Health Association [259], the College of Physicians and Surgeons of Ontario [262], and the Registered Nurses’ Association of Ontario [263]. Although these organizations acknowledge the importance of health literacy, most do not advocate for specific approaches toward addressing it beyond awareness and the use of plain language in written health information. Over the last 20 years, approaches to the challenge of inadequate health literacy have been to mitigate its effects through use of plain language communication and healthcare provider training with a focus on the use of teach-back
[264]. Although these approaches have demonstrated some impact, new approaches are needed that take a broader view of the healthcare system [116].

One such view to consider is whether it is reasonable that an individual is required to have high health literacy in order to access healthcare and experience optimal outcomes. Much work has surfaced in recent years about the concept of the Health Literate Health Care Organization [265, 266]. This body of work recognizes that health care organizations are too complex for individuals with inadequate health literacy to access and advocates for approaches to mitigate the effects of complex health care systems on patient outcomes.

As such, another consideration for cancer health policy is the complexity of the cancer treatment system. In a society with high prevalence of inadequate health literacy, vital health services should be straightforward to access and not require high levels of health literacy or self-efficacy. Untangling the complexity of cancer care is a worthwhile exercise and would very likely increase equitable access to care and, at the same time, result in significant cost savings and improved cancer outcomes. Efforts should be directed toward simplifying access to cancer care.

### 7.2 Implications for Practice

This study found that participants with higher self-efficacy had higher chemotherapy self-management scores compared to participants with low self-efficacy. This is an important finding for two reasons. First, it contributes to a body of knowledge about the role of self-efficacy to health outcomes in cancer. Second, because self-efficacy is a construct that can be cultivated and built while patients are in the cancer care system, it has the potential to improve outcomes and multiple interventions have been developed and evaluated to demonstrate the effect of healthcare provider training in this area [267]. Building patient self-efficacy in the context of chemotherapy self-management could be particularly helpful both in the context of the cancer centre and in the domain of oral chemotherapy management at home where patients are required to take on significant responsibility for self-management.
7.3 Implications for Research

This study is among the first to explore the association of health literacy in cancer self-management behaviours and highlights some important considerations for future research in this field. One consideration is that engaging cancer patients with inadequate health literacy in research may be even more challenging than was previously thought. If cancer patients with inadequate health literacy are not accessing health services at a rate that is statistically meaningful, research in this area may need to extend beyond cancer centres and into community. In addition, individuals with inadequate health literacy due to English language barriers may be excluded from participating in research.

A second consideration is that current gold standard measures of health literacy fail to adequately capture the multiple dimensions of health literacy and as such cannot provide meaningful data for the incidence of health literacy in a population. A measure of health literacy that encompasses more than just reading comprehension is needed [116]. In addition, since the cancer treatment system is complex, the development of a specific measure of cancer health literacy would be helpful. Although recently some measures of cancer health literacy have been developed, to date they account only for patient level deficits rather than taking into account deficits within the systems as well as provider communication deficits [114, 268]. The development of a thorough measure of cancer health literacy could contribute to growth in the field and an evolution in equitable cancer care.

A third consideration is that self-efficacy holds much potential for improving cancer patient outcomes. If patients with higher self-efficacy can self-manage side effects better than patients with low self-efficacy, strategies can be developed to build cancer patient self-efficacy that target specific and important self-management behaviours. This has research implications as these strategies will need to be evaluated and tested in the field.

The fourth and final consideration is that the concept of self-management in cancer is in its infancy and this may, in part be both cause and effect of the dearth of measures of important cancer self-management behaviours.
This study advocates for further development in the measurement of cancer health literacy and cancer self-management behaviours. It further advocates for more research to explore the potential of self-efficacy in cancer self-management. This dissertation research has laid a foundation for a future program of research in health literacy, self-efficacy, and cancer.

7.4 Future Directions

The results of this study provide several opportunities for future research. First, the development and validation of a more comprehensive measure of cancer health literacy is needed. A measure such as this would take into account more than patient reading skills and account for health system factors, healthcare provider factors, as well as patient factors, to more accurately appreciate the complexity of cancer health literacy [106, 116].

Second, research is needed to explore, in depth, who is accessing cancer care services in Ontario and who is not. It is clear from the literature that patients with inadequate health literacy are accessing cancer screening programs at lower rates than their higher health literate counterparts and, subsequently these individuals are presenting to the cancer care system with more advanced disease, experience worse outcomes and contribute significantly to the cost of cancer services [14-16, 20, 26]. It is unknown currently in Ontario what the impact of inadequate health literacy is both at the individual level and the systems level; establishing this could drive more equitable approaches to cancer care delivery as well as more cost-effective strategies.

A third opportunity for future research is to initiate a Province-wide evaluation of Regional Cancer Centres for health literate practices. Several measures have been developed and evaluated for the purpose of evaluating health care organizations for health literate practices [131, 265, 269] and having a provincial body like Cancer Care Ontario, positions Ontario to be a leader in this field. Results of a Province-wide evaluation could set priorities for cancer system reforms that could mitigate the impact of inadequate health literacy including the potential for individuals with inadequate health literacy to access cancer care at a lower rate than their health literate counterparts.
A fourth opportunity for research is in the domain of instrument development for important cancer self-management behaviours. The field of self-management has been slow to develop in cancer [23, 27, 38, 39]. This may be attributed to the emerging classification of cancer as a chronic disease since self-management in other diseases is focused largely on chronicity [23, 32, 33]. In cancer there is significant need for patients to engage in self-management behaviours during the acute phase of treatment as such, focused measures for this period could help to build a body of knowledge in cancer self-management [34].

A fifth research opportunity is to further explore the role of various situation-specific forms of cancer self-efficacy on chemotherapy self-management behaviours. The potential to build self-efficacy into cancer care provision holds promise for cancer self-management and as such, harnessing self-efficacy to improve patient self-management skills could be advantageous.

This is one of the first studies to explore the association between health literacy and cancer self-management behaviours in the acute care setting and the findings have important implications for health policy, practice and research.
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Facilitating client Centred Learning with a Focus on the L.E.A.R.N.S. Model of Care Delivery


## Variable Table

<table>
<thead>
<tr>
<th>Variable</th>
<th>Function</th>
<th>Operational Definition</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Independent</td>
<td>What is your gender?</td>
<td>Nominal: 1=Male 2=Female 3= Other</td>
</tr>
<tr>
<td>Age</td>
<td>Independent</td>
<td>What is your present age?</td>
<td>Interval: 18-120</td>
</tr>
<tr>
<td>Education</td>
<td>Independent</td>
<td>What is the highest level of schooling that you have completed?</td>
<td>Ordinal: 1= grades 1-8 2= grades 9-11 3= high school 4= college/university</td>
</tr>
<tr>
<td>Income</td>
<td>Independent</td>
<td>What is your household’s total annual income for the most recent year?</td>
<td>Ordinal: 1=Less than $25,000 2=$25,000 to $49,999 3=$50,000 to $74,999 4=$75,000 to $99,999 5=More than $99,999 6=I prefer not to answer</td>
</tr>
<tr>
<td>Language</td>
<td>Independent</td>
<td>What language is most often spoken in your home?</td>
<td>Nominal: 1= English 2= Other:</td>
</tr>
<tr>
<td>Country of Birth</td>
<td>Independent</td>
<td>What is the country of your birth?</td>
<td>Nominal: 1=Canada 2=Other:</td>
</tr>
<tr>
<td>Population Group</td>
<td>Independent</td>
<td>What is your population group? Categories taken from Canadian Census 2010.</td>
<td>Nominal: 1= Aboriginal (i.e. Inuit, Métis, North American Indian) 2= Arab/West Asian (i.e. Armenian, Egyptian, Iranian,)</td>
</tr>
<tr>
<td>Cancer Type</td>
<td>Universal</td>
<td>What was the original site of your cancer?</td>
<td>Nominal: Open field</td>
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</tr>
<tr>
<td>Health Literacy</td>
<td>Independent</td>
<td>Validated instrument: The Short Test of Functional Health Literacy (S-TOFHLA) 36 items</td>
<td></td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>Independent</td>
<td>Validated Instrument: The Cancer Behaviour Inventory-Brief (CBI-B) 14-items</td>
<td>A component score is taken from the arithmetic mean of all 14-items</td>
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<tr>
<td>Symptom Severity and Symptom Interference</td>
<td>Independent / Confounding</td>
<td>Validated Instrument: The MD Anderson Symptom Assessment Inventory (MDASI) 13-item and 6 item</td>
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<tr>
<td>Chemotherapy Self-Management</td>
<td>Dependent</td>
<td>Validated instrument: The Leuven Questionnaire</td>
<td>Continuous: Computes a self-care score that reflects to</td>
</tr>
</tbody>
</table>
| Health Service Utilization | Dependent | Stanford Patient Education Research Centre – Health Services Use Scale, 4 items | Continuous:  
Number of visits to a healthcare provider over the course of chemotherapy treatment;  
Number of visits to the hospital emergency room over the course of chemotherapy treatment;  
Number of times hospitalized over the course of chemotherapy treatment;  
Number of nights spent in a hospital over the course of chemotherapy treatment. |
<table>
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<tbody>
<tr>
<td>for Patient Self-Care During Chemotherapy (L-PaSC) 22 items</td>
<td>what extent the respondent performs adequate self-care during chemotherapy.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Literature Review 2: Search Terms

1. `exp information literacy/` (1210)
2. `Health Literacy/ [a narrower heading under information literacy]` (1148)
3. `Computer Literacy/` (1366)
4. `limit 3 to yr="1992 - 2011"` (1227)
5. `Health Knowledge, Attitudes, Practice/` (65933)
6. `Educational Status/` (37223)
7. `health literacy.tw.` (1899)
8. `information literacy.tw.` (175)
9. `literacy.tw.` (6813)
10. `1 or 2 or 4 or 5 or 6 or 7` (102208)
11. `1 or 2 or 4 or 5 or 6 or 9` (105138)
12. `exp Neoplasms/` (2428281)
13. `cancer*.tw.` (930514)
14. `tumor*.tw.` (863832)
15. `tumour*.tw.` (185137)
16. `carcin*.tw.` (523404)
17. `neoplas*.tw.` (179311)
18. `metasta*.tw.` (274161)
19. `oncolog*.tw.` (68307)
20. `exp Medical Oncology/` (13478)
21. `exp Radiation Oncology/` (2376)
22. `neoplasm staging/` (111979)
23. `or/12-22` (2803506)
24. `exp Self Care/` (37161)
25. `Self car*.tw.` (8805)
26. `Selfcar*.mp.` (72)
27. `Self manag*.tw.` (6826)
28. `Self monitor*.tw.` (3844)
29. `Selfmonitor*.tw.` (12)
30. `Selfmanag*.tw.` (12)
31. `Selfadminstrat*.tw.` (0)
32. `Self adminstrat*.tw.` (3)
33. `Self medicat*.tw.` (2384)
34. `Selfmedicat*.tw.` (6)
self efficacy/(10682)
self efficacy.tw. (10282)
exp Self-Help Devices/ (7930)
self help.tw. (4084)
selfhelp.tw. (13)
Self-Help Groups/ (7495)
Self-Care Units/ (116)
self regulat*.tw. (5228)
selfregulat*.tw. (19)
or/24-43 (83171)
11 and 23 and 44 (522)
literacy.mp. (8377)
1 or 4 or 5 or 6 or 46 (105250)
23 and 47 (9201)
44 and 48 (522)
remove duplicates from 49 (511)
limit 50 to english language (507)
limit 51 to yr="1992 -Current" (497)
Questionnaire Package

**Research Study:** The association of health literacy on chemotherapy self-management and health service utilization

**Purpose:** This study aims to understand whether patient ability to cope with cancer is affected by their ability to understand and act on health information. We will use the collected information to better respond to the needs of future patients and family members.

**Procedure:**
We are looking for people who are 18 years of age and older, who have been diagnosed with cancer to complete a questionnaire about their ability to understand health information and cope with cancer. The questionnaire will not collect any identifying information. All responses will be completely anonymous and confidential.

If you wish to participate, please fill out the questionnaire. It will take between 40-50 minutes. The questionnaire will ask you for background information about yourself, your cancer diagnosis, your understanding of health information through two scenarios and your feelings about coping with chemotherapy.

This research is being conducted by Janet Papadakos, a PhD student at the University of Toronto, under the supervision of Dr. Doris Howell, Health Services Researcher at the Princess Margaret Cancer Centre.

Please note that we will not contact you about this study. Your consent to participate simply involves the completion of the questionnaire.

Should you have any questions or concerns about this study, or your rights as a research participant, please contact the Chair of the University Health Network Research Ethics Board (REB) at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
If you wish to reach the study team, you can contact us at 416-581-7764.
ATTENTION: Please do not put your name on the survey.

Participant ID#:

Part One:
We would like to ask a few questions about you for statistical purposes. This information will only be viewed by the study team and not be shared. This section will help us determine how representative the patients are who complete this questionnaire.

1. What is your gender?
☐ Male
☐ Female

2. What type of cancer have you been diagnosed with?
Check all that apply.
☐ Bladder cancer
☐ Breast cancer
☐ Colon and Rectal cancer
☐ Endometrial cancer
☐ Kidney (renal cell) cancer
☐ Leukemia
☐ Lung cancer
☐ Melanoma
☐ Non-hodgkin lymphoma
☐ Pancreatic cancer
☐ Thyroid cancer
☐ Other (please specify):
(Categories taken from the National Cancer Institute list of most common cancers, 2012)

3. Just before you were diagnosed with cancer, what was your work status?
☐ Working
☐ Student
☐ Retired
☐ Homemaker
☐ On disability
☐ Unemployed
☐ Other (please specify):

4. What is your household’s total annual income for the most recent year?
☐ Less than $25,000
☐ $25,000 - $49,999
☐ $50,000 – $74,999
☐ $75,000 – $99,999
☐ More than $100,000
6. What is the highest level of schooling that you completed?

☐ No formal education
☐ Grade school
☐ Some high school
☐ High school
☐ Some college/university
☐ College/university
☐ Graduate school
☐ Other (please specify):

7. What is your present age?

8. Where were you born?

☐ Canada
☐ Other (please specify):

9. Which of the following best describes your population group?

☐ Aboriginal (i.e. Inuit, Métis, North American Indian)
☐ Arab/West Asian (i.e. Armenian, Egyptian, Iranian, Lebanese, Moroccan)
☐ Black (i.e. African, Haitian, Jamaican, Somali)
☐ Chinese
☐ Filipino
☐ Japanese
☐ Korean
☐ Latin American
☐ South Asian
☐ South East Asian
☐ White (Caucasian)
☐ Other (please specify):
(Categories taken from Canadian Census 2015.)

10. What language is most often spoken in your home?
   ☐ English
   ☐ Other (please specify):

11. Are you comfortable receiving health information in English?
   ☐ Yes
   ☐ No

12. In the time since you started chemotherapy treatment, how many times have you visited a healthcare provider (nurse, doctor etc.), including visits to the emergency room?
   visits.

13. In the time since you started chemotherapy, how many times have you gone to a hospital emergency room?
   times.

14. In the time since you started chemotherapy treatment, how many times have you stayed overnight or longer in a hospital?
   times.

15. In the time since you started chemotherapy, how many TOTAL nights have you spent in the hospital?
   nights.

Part 2:
Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others...
want you to say.

1. I can always manage to solve difficult problems if I try hard enough.

   □ Not at all true  □ Hardly true  □ Moderately true  □ Exactly True

2. If someone opposes me, I can find the means and ways to get what I want.

   □ Not at all true  □ Hardly true  □ Moderately true  □ Exactly True

3. It is easy for me to stick to my aims and accomplish my goals.

   □ Not at all true  □ Hardly true  □ Moderately true  □ Exactly True

4. I am confident that I could deal efficiently with unexpected events.

   □ Not at all true  □ Hardly true  □ Moderately true  □ Exactly True

5. Thanks to my resourcefulness, I know how to handle unforeseen situations.

   □ Not at all true  □ Hardly true  □ Moderately true  □ Exactly True

6. I can solve most problems if I invest the necessary effort.

   □ Not at all true  □ Hardly true  □ Moderately true  □ Exactly True
7. I can remain calm when facing difficulties because I can rely on my coping abilities.

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Exactly True

8. When I am confronted with a problem, I can usually find several solutions.

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Exactly True

9. If I am in trouble, I can usually think of a solution.

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Exactly True

10. I can usually handle whatever comes my way.

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Exactly True

Part 3:
Here are some medical instructions that you or anyone might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing, a blank line has been drawn and 4 words that could go in the blank appear just below it. Circle the word from the list below the blank that best fits in the sentence.

3. a): X-Ray Preparation

Your doctor has sent you to have a ______ X-ray.

1. stomach
2. diabetes
3. stitches
4. germs

You must have an ______ stomach when you come for ______.

1. asthma a) is.
2. empty b) am.
3. incest c) if.
4. anemia d) it.

The X-ray will ______ from 1 to 3 ______ to do.

a) take a) bed
b) view b) brains
c) talk c) hours
d) look d) diets

The Day Before the X-Ray

For supper have only a ______ snack of fruit, ______ and jelly, with coffee or tea.

1. little a) toes
2. broth b) throat
3. attack c) toast
4. nausea d) thigh
After , you must not or drink anything at until after you

a) minute  a) easy  a) ill
b) midnight  b) ate  b) all
c) during  c) drank  c) each
d) before  d) eat  d) any

have the X-ray.

1. are
2. has
3. had
4. was

The Day of the X-Ray

Do not eat .

1. appointment.
2. walk-in.
3. breakfast.
4. clinic.

Do not , even .

a) drive, a) heart.
b) drink, b) breath.
c) dress, c) water.
d) dose, d) cancer.

If you have any , call the X-ray at 616-4500.

a) answers, a) Department
b) exercises,  
	b) Sprain  
c) tracts,  
	c) Pharmacy  
d) questions,  
	d) Toothache  

3. b): Health Care Coverage  
Note: These questions were written in the United States and do not reflect the Canadian health system. Please answer as best as you can.

I agree to give correct information to if I can receive Medicaid.  
1. hair  
2. salt  
3. see  
4. ache  

I to provide the country information to any statements given in this  
a) agree  
b) probe  
c) send  
d) gain  
a) hide  
b) risk  
c) discharge  
d) prove

and hereby give permission to the to get such proof. I  
1. emphysema  
2. application  
3. gall bladder  
4. relationship  
a) inflammatory  
b) religion  
c) iron  
d) county  
a) investigate  
b) entertain  
c) understand  
d) establish

that for Medicaid I must report any in my circumstances within (10)  
a) changes  
a) three
b) hormones

b) one

c) antacids

c) five

d) charges

d) ten

days of becoming

of the change.

1. award

2. aware

3. away

4. await

I understand

if I DO NOT like the made on my case, I have the

a) thus

a) marital

b) this

b) occupation

c) that

c) adult

d) than

d) decision

to a fair hearing.

1. bright

2. left

3. wrong

4. right

I can a hearing by writing or the county where I applied.

a) request

a) counting

b) refuse

b) reading

c) fail

c) calling

d) mend

d) smelling
If you TANF for any family, you will have to a different

a) wash a) member, a) relax
b) want b) history, b) break
c) cover c) weight, c) inhale
d) tape d) seat belt, d) sign

application form.

, we will use the on this form to determine your .

a) Since, a) lung a) hypoglycemia.
b) Whether, b) date b) eligibility.
c) However, c) meal c) osteoporosis.
d) Because, d) pelvic d) schizophrenia.
### Part 4: How severe are your symptoms?

People with cancer frequently have symptoms that are caused by their disease or by their treatment. We ask you to rate how severe the following symptoms have been *in the last 24 hours*. Please fill in the circle below from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be) for each item.

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<tr>
<th></th>
<th>Not present</th>
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<th>10</th>
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</thead>
<tbody>
<tr>
<td>1. Your <strong>pain</strong> at its WORST?</td>
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<td>2. Your <strong>fatigue</strong> (tiredness) at its WORST?</td>
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<td>3. Your <strong>nausea</strong> at its WORST?</td>
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<td>4. Your <strong>disturbed sleep</strong> at its WORST?</td>
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<td>5. Your feelings of being <strong>distressed</strong> (upset) at its WORST?</td>
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<td>6. Your <strong>shortness of breath</strong> at its WORST?</td>
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<td>7. Your problem with <strong>remembering</strong> things at its WORST?</td>
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<td>8. Your problem with <strong>lack of</strong> appetite at its WORST?</td>
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<td>9. Your feeling <strong>drowsy (sleepy)</strong> at its WORST?</td>
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<td>10. Your having a <strong>dry mouth</strong> at its WORST?</td>
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<td>11. Your feeling <strong>sad</strong> at its WORST?</td>
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<td>12. Your <strong>vomiting</strong> at its WORST?</td>
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<tr>
<td>13. Your <strong>numbness or tingling</strong> at its WORST?</td>
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</table>

**Part 5:**

This part of the questionnaire contains many things that a person might do when receiving treatment for cancer. We are interested in your judgment of how confident you are that you can accomplish those things. Make sure your ratings accurately reflect your confidence whether or not you have done it in the past. So, your ratings reflect your confidence that you
can do these things now (or in the near future).
Please read each numbered item. Then rate that item on how confident you are that you can accomplish that behaviour. Circle a number on the scale.

If you circle a "1" you would be stating that you are not at all confident that you can accomplish that behaviour. If you circle a "9" you would be stating that you are totally confident that you can accomplish that behaviour. Numbers in the middle of the scale indicate that you are moderately confident that you can accomplish that behaviour.

Please rate all items. If you are not sure about an item please rate it as best you can

<table>
<thead>
<tr>
<th>1. Maintaining Independence</th>
<th>NOT AT ALL CONFIDENT</th>
<th>MODERATELY CONFIDENT</th>
<th>TOTALLY CONFIDENT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3</td>
<td>4 5 6</td>
<td>7 8 9</td>
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</table>

<table>
<thead>
<tr>
<th>2. Maintaining a positive attitude</th>
<th>NOT AT ALL CONFIDENT</th>
<th>MODERATELY CONFIDENT</th>
<th>TOTALLY CONFIDENT</th>
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<tbody>
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<td></td>
<td>1 2 3</td>
<td>4 5 6</td>
<td>7 8 9</td>
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<tr>
<td>3. Maintaining a sense of humor</td>
<td>NOT AT ALL CONFIDENT</td>
<td>MODERATELY CONFIDENT</td>
<td>TOTALLY CONFIDENT</td>
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<td>4 5 6</td>
<td>7 8 9</td>
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<table>
<thead>
<tr>
<th>4. Expressing feelings about cancer</th>
<th>NOT AT ALL CONFIDENT</th>
<th>MODERATELY CONFIDENT</th>
<th>TOTALLY CONFIDENT</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3</td>
<td>4 5 6</td>
<td>7 8 9</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Putting things out of my mind at times</th>
<th>NOT AT ALL CONFIDENT</th>
<th>MODERATELY CONFIDENT</th>
<th>TOTALLY CONFIDENT</th>
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<tr>
<td></td>
<td>1 2 3</td>
<td>4 5 6</td>
<td>7 8 9</td>
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<table>
<thead>
<tr>
<th>6. Maintaining activities (work, home, hobbies, social)</th>
<th>NOT AT ALL CONFIDENT</th>
<th>MODERATELY CONFIDENT</th>
<th>TOTALLY CONFIDENT</th>
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<tr>
<td></td>
<td>1 2 3</td>
<td>4 5 6</td>
<td>7 8 9</td>
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<table>
<thead>
<tr>
<th>7. Trying to be calm throughout treatments and not allowing scary thoughts to upset me</th>
<th>NOT AT ALL CONFIDENT</th>
<th>MODERATELY CONFIDENT</th>
<th>TOTALLY CONFIDENT</th>
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<tr>
<td></td>
<td>1 2 3</td>
<td>4 5 6</td>
<td>7 8 9</td>
</tr>
<tr>
<td>8. Actively participating in treatment decisions</td>
<td>NOT AT ALL CONFIDENT</td>
<td>MODERATELY CONFIDENT</td>
<td>TOTALLY CONFIDENT</td>
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<td>1</td>
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</table>

<p>| 9. Asking physicians questions | NOT AT ALL CONFIDENT | MODERATELY CONFIDENT | TOTALLY CONFIDENT |
|  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
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<tbody>
<tr>
<td>10. Seeking social support</td>
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<td>NOT AT ALL</td>
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<td>MODERATELY</td>
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<td>11. Sharing my worries or concerns with others</td>
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<td>NOT AT ALL</td>
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<tr>
<td>12. Managing nausea and vomiting (whether or not I have had these</td>
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<td>problems in the past)</td>
<td>NOT AT ALL</td>
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<td>13. Coping with physical challenges</td>
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<td>NOT AT ALL</td>
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<td>14. Trying to be calm while waiting</td>
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<td>NOT AT ALL</td>
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<td>CONFIDENT</td>
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<tr>
<td>at least one hour for my appointment</td>
<td>1</td>
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</table>
## Part 6. Involvement in Your Care

The questions below contains many things that a person might do when receiving treatment for cancer. We are interested in your opinion on the statements below.

Please read each numbered statement. Then rate that item on how much you disagree or agree with the statement. Circle the words in the column that best matches your agreement. If you circle “Disagree Strongly” you would be stating that you strongly disagree with the statement. If you circle “Agree Strongly” you would be stating that you strongly agree with the statement. Words in the middle of the scale indicate that you moderately disagree or agree with the statement.

Please rate all items. If you are not sure about an item please rate it as best you can.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Agree</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When all is said and done, I am the person who is responsible for managing my health condition.</td>
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<tr>
<td>2. Taking an active role in my own health care is the most important factor in determining my health and ability to function.</td>
<td></td>
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<td>3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition.</td>
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<tr>
<td>4. I know what each of my prescribed medications do.</td>
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</table>
5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.

6. I am confident I can tell my health care provider concerns I have even when he or she does not ask.

7. I am confident that I can follow through on medical treatments I need to do at home.

8. I understand the nature and causes of my health condition(s).

9. I know the different medical treatment options available for my health condition.

10. I have been able to maintain the lifestyle changes for my health that I have made.

11. I know how to prevent further problems with my health condition.
12. I am confident I can figure out solutions when new situations or problems arise with my health condition.

Disagree Disagree Agree Agree N/A
Strongly Strongly

13. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress.

Disagree Disagree Agree Agree N/A
Strongly Strongly

Strongly Strongly
# Part 7. Managing Chemotherapy

This is the last part of the questionnaire. These last questions assess your self-care during your treatment. Please do not rely on help from sources or other people to complete it. It is important that the questionnaire provides a true picture of your self-care during your treatment.

## 1. Do you take any of the following self-care measures?

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<th>Mostly</th>
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<td>Ensuring good dental health and mouth hygiene by brushing your teeth at least twice a day</td>
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<td>During chemotherapy until a few days after administration of the chemotherapy disposing of incontinence supplies, sanitary towels, tampons, etc. in a plastic bag</td>
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<td>☐</td>
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<tr>
<td>chicken pox, cold sores or a cold</td>
<td>Taking your temperature when you feel ill</td>
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<td>Taking medication without consulting a doctor</td>
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<td></td>
<td>Taking measures to prevent you or your partner becoming pregnant</td>
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</table>

2. **Please indicate what do you in the following situations.** Tick one box only

You suddenly feel short of breath after only a little physical activity. What do you do?

- I immediately contact my doctor / health centre or family doctor
- I mention the problem during my next hospital visit or doctor's appointment
- I wait a few days before I take some action
- I don't do anything, the symptoms are not relevant for my further treatment
- I don't know

You have a fever of 38.5. What do you do?

- I immediately contact my doctor / health centre or family doctor
- I mention the problem during my next hospital visit or doctor's appointment
- I wait a few days before I take some action
- I don't do anything, the symptoms are not relevant for my further treatment
- I don't know
You have diarrhea three times per day. What do you do?

☐ I immediately contact my doctor / health centre or family doctor
☐ I mention the problem during my next hospital visit or doctor’s appointment
☐ I wait a few days before I take some action
☐ I don’t do anything, the symptoms are not relevant for my further treatment
☐ I don’t know

You have vomited five times in one single day and you can’t keep any water down. What do you do?

☐ I immediately contact my doctor / health centre or family doctor
☐ I mention the problem during my next hospital visit or doctor’s appointment
☐ I wait a few days before I take some action
☐ I don’t do anything, the symptoms are not relevant for my further treatment
☐ I don’t know

You feel pins and needles in your fingertips. What do you do?

☐ I immediately contact my doctor / health centre or family doctor
☐ I mention the problem during my next hospital visit or doctor’s appointment
☐ I wait a few days before I take some action
☐ I don’t do anything, the symptoms are not relevant for my further treatment
☐ I don’t know

3. Does your treatment (also) include chemotherapy in the form of tablets to be taken by mouth?

☐ No Please go to question 4.
☐ I don’t know Please go to question 4.
☐ Yes Please answer the question below:

What percentage of these doses have you taken correctly and at the right moment of the day? Please indicate with a circle around the percentage below.
4. Did you doctor prescribe any medication to treat side effects of the chemotherapy?

☐ No Please go to question 5.
☐ I don’t know Please go to question 5.
☐ Yes Please answer the question below:

If so, what percentage of the medication to treat side effects have you taken correctly?
Please indicate with a circle around the percentage below.
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

5. Did you receive self-care advice (e.g. using mouthwashes, dealing with tiredness) from your caregiver or in information leaflets?

☐ No Please go to question 6.
☐ Yes Please answer the question below:

If so, what percentage of the self-care advice you received or read about did you follow?
Please indicate with a circle around the percentage below.
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Side Effects
Underneath are some questions about possible side effects during treatment with chemotherapy. In the first part of each question you are asked whether you experienced the particular side effect and how serious this side effect was at its worst. In the second part of the question you are asked what actions you took to relieve the side effects. In case
you haven’t had this side effect since the start of the treatment, please go to the next question.

6. Since the start of the treatment, how serious were the INFECTIONS IN THE MOUTH (e.g. MOUTH SORES) at their worst?

- I haven’t had any infections in my mouth yet. Please go to question 7.
- I have (have had) some problems with this, but not to such an extent that I can’t (couldn’t) eat.
- I have (have had) a lot of problems with mouth infections and I have (have had) difficulties eating.
- I have (have had) so many problems with mouth infections that I can’t (couldn’t) eat or drink.

If you have (had) mouth infections, what do (did) you do to treat it?

- Nothing
- Inspection of the mouth (checking for mouth sores or injuries)
- Discuss it with the doctor or nurse
- Use mouth washes
- Use soft toothbrush
- Rinse with fresh lemon juice or with orange juice
- Other:

7. Since the start of the treatment, how serious were the SKIN PROBLEMS (e.g. dry skin, itch, rash, redness etc.) at their worst?

- I haven’t noticed any changes in my skin. Please go to question 8.
- I don’t have (haven’t had) any serious skin problems.
- I have (have had) skin problems, but not to such an extent that I can’t (couldn’t) go about my daily activities.
I have (have had) skin problems to such an extent that I can’t (couldn’t) perform my daily activities.

If you have (had) skin problems, what do (did) you do to treat it?

- Nothing
- Discuss with the doctor or nurse
- Take hot showers or baths
- Protect my skin against the sun
- Use oily or moisturizing creams
- Avoid extreme temperatures
- Other:

8. Since the start of the treatment, how serious was the NAUSEA at its worst?

- I haven’t been nauseous since the start of treatment. Please go to question 9.
- I have (have had) less appetite due to nausea, but my eating patterns have remained the same.
- I often feel nauseous, I eat and drink less and I’m losing weight because of it.
- I suffer from severe nausea; it affects my eating patterns to such an extent that I cannot take in sufficient food and fluids.

If you are (were) nauseous, what do (did) you do to treat it?

- Nothing
- Discuss it with the doctor or nurse
- Eat small but frequent meals
- Eat spicy food
- Snack between meals if it goes well
- Take prescribed medication. Please specify:
- Other:
9. Since the start of the treatment, how serious was the CONSTIPATION at its worst?

☐ My bowel movements haven’t changed. I don’t have fewer stools than before and I don’t have any difficulty passing stool. Please go to question 10.

☐ Since the start of the treatment I have experienced some difficulty passing stool.

☐ Since the start of the treatment I have clearly experienced difficulties passing stool but not to such an extent that it affects my daily activities.

☐ Since the start of the treatment I have experienced such difficulties passing stool that it affects my daily activities.

If you have (had) constipation, what do (did) you do to avoid or treat it?

☐ Nothing

☐ Drink more

☐ Eat foods rich in fiber, such as brown bread, wholegrain pasta, raw vegetables etc.

☐ Eat low fiber food, such as white bread, ripe bananas etc.

☐ Report it to the doctor or nurse

☐ Take medication. Please specify:

☐ Stop taking certain medication. Please specify:

☐ Other:

10. Since the start of the treatment, how serious was the DIARRHEA at its worst?

☐ I haven’t had any diarrhea yet. Please go to question 11.

☐ I have (have had) up to 4 loose bowel movements per day.

☐ I have (have had) 4 to 6 loose bowel movements per day.

☐ I have (have had) more than 7 loose bowel movements per day.

☐ The diarrhea is so serious that I can no longer perform daily activities.

If you have (had) diarrhea, what do (did) you do to avoid or treat it?

☐ Nothing
Drink extra fluids
Eat foods rich in fiber, such as brown bread, wholegrain pasta, raw vegetables etc.
Eat low fiber food, such as white bread, ripe bananas etc.
Report it to the doctor or nurse
Take medication. Please specify:
Stop taking certain medication. Please specify:
Other:

11. Since the start of the treatment, how serious was the TIREDNESS at its worst?
Please indicate the worst tiredness on the scale below, where
0 = no tiredness
10 = the worst tiredness that you can imagine
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
If you have indicated 0, please go to question 12.

If you suffer (suffered) from tiredness, what do (did) you do to deal with it?
Nothing
Set my limits
Balance rest and activities
Drink coffee or other caffeinated drinks
Organize help
Discuss it with the doctor or nurse
Other:

12. Since the start of the treatment, how serious was the PAIN at its worst?
Please indicate the worst tiredness on the scale below, where
0 = no tiredness
10 = the worst tiredness that you can imagine

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

If you have indicated 0, the questionnaire ends here.

If you have (had) pain, what do (did) you do to stop it?
☐ Nothing
☐ Discuss with the doctor or nurse
☐ Take medication
☐ Deal with the cause of it
☐ Other:

We sincerely thank you for participating in this study. Your contribution is very valuable as we try to improve services at the Princess Margaret Cancer Centre.

If you are affected by the content of this questionnaire in such a way that you would like to seek professional help, please contact the department of psychosocial oncology at: 416-946-4525

If you would like to receive a copy of the results of this study once it is completed, please contact the study team at: 416-581-7764
## Descriptive Statistics: Country of Birth

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United States 6 2.8
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Descriptive Statistics: Chemotherapy Drugs

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