

Final Report

Impact of Interlink Nursing on Patient Supportive Care Outcomes

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Executive Summary

Introduction

Supportive cancer care (SCC) in Ontario remains problematic due to the fragmentation of services that result in discontinuities of care for patients, and ultimately in unmet supportive care needs (Canadian Cancer Society, 2003). In March 2003, the Supportive Cancer Care Research Unit submitted the results of the study, *Coordinating Supportive Cancer Care in the Community* (Brazil et al., 2003) to the Ministry of Health and Long-Term Care. This study examined supportive cancer care at a system level and reported a substantial lack of coordinated care in the areas of comprehensiveness, accessibility, and compatibility. One of the most significant recommendations from the study included the establishment of specialized, supportive cancer care community nurses who would be responsible for coordinating and facilitating client care. A product of this study was the identification of a single community-based, not-for-profit supportive cancer care service delivery program in Ontario, *Interlink Community Cancer Nurses (Interlink)* that provided care across the entire cancer continuum.

As there was little empirical evidence about the potential effectiveness of such a program (Brazil et al., 2004; Canadian Breast Cancer Initiative, 2002; Hollander & Prince, 2002; Cancer Services Implementation Committee, 2001; Leatt, Pink, & Guerriere, 2000), a subsequent study, *An Evaluation of the Effectiveness of a Specialized Nursing Case Management Program in Coordinating Supportive Cancer Care in the Community* (Sussman et al., 2004) was undertaken. This study resulted in an in-depth examination of a community-based specialized oncology nursing model as an example of such a model of care. Results showed that the model had the potential to enhance the coordination of community-based supportive cancer care service delivery and thus reduce the discontinuities experienced by patients (Brazil et al., 2004) and their families by “creating a system of support around the patient and family”.

The current study, conducted by the Supportive Cancer Care Research Unit (SCCR Unit) in partnership with the Ministry of Health and Long-Term Care of Ontario represents the next step in evaluating the impact of the specialized oncology-nursing model on key patient supportive care outcomes. The objectives of the current study were to determine whether patients who receive care by a community-based specialized oncology nurse have: (*primary*) A reduction in unmet supportive care needs; and (*secondary*) improvements in quality of life and continuity of supportive care. An additional objective was to determine the effect of the nursing intervention on patient health service utilization. The planned sample was 100 respondents. This is a final report on the 109 respondents enrolled in the study.

Methods

This study is a repeated measures longitudinal cohort design, with assessments at baseline (T1), four (T2) and eight (T3) weeks. Potential participants were identified at the time of referral to the *Interlink* program and these consisted of all referrals, meeting the study inclusion criteria, made to Interlink between August 2004 and March 2005 and September 2005 to February 2006. The validated assessment tools used to obtain measures along the patient's care trajectory include: *Supportive Cancer Needs Survey Short Form 34* (SCNS-SF34), *Quality of Life* (EORTC QLC-30_(v3)), *Continuity and Coordination of Care Questionnaire* (CCCQ), and a service utilization instrument that was customized to reflect the needs of patients in this study. Trained interviewers collected data via telephone surveys. The experiences of participants were recorded at intake to the program (T1) and at four (T2) and eight (T3) weeks after intake.

Results

The most important finding of this study is the confirmation of our hypothesis that patients who receive specialized oncology nursing will have improvements in the most important supportive cancer care outcome, having their needs met across the spectrum

of supportive care domains. Patients' need for psychological support, informational needs, daily living, patient care and support needs were compared to baseline at 4 weeks and 8 weeks following introduction of *Interlink* care. A significant reduction in patients unmet needs for psychological support, informational needs, and patient care were seen at 4 weeks, which continued to improve at 8 weeks. The need for physical support and daily living also continued to improve and bordered on statistical significance. It was estimated that as many as 10-15% of patients experienced improvements in these domains.

In addition to the impact on patient supportive care needs important changes were also observed in patients' quality of life. Although no improvement was observed in patients' global health or physical functioning, no deterioration was seen. This is an important observation as the expectation with such an advanced disease population is steady deterioration in quality of life over time as suggested by a number of studies (Peters & Sellick, 2006; Grunfeld, 1999). Patients' physical role functioning improved over the 8-week period and important trends were seen in social functioning. Consistent with the improvement in role functioning patients' symptoms, in particular fatigue, nausea, vomiting, pain, insomnia, appetite loss, and constipation all decreased over the 8-week period. These observations are consistent with the meeting of patients' needs and the support that they received from the *Interlink* nursing program.

While the study did not demonstrate a dramatic improvement in the continuity of care over time, important trends were observed in health care providers knowledge about the patient, interpersonal communication and support of patient preferences which we can attribute to the *Interlink* program as a majority of participants indicated that the nurse was instrumental in helping them in these various areas.

The corresponding data on service utilization was interesting. Normally the introduction of supportive care interventions can often result in a paradoxical increase in use of healthcare resources. In our previous study where patients with advanced breast cancer were offered early referral to community care access centres, the number of

acute care encounters significantly increased (Grunfeld, 1999). In the current study of this specialized nursing oncology program, which provides some direct care services and coordinates other services provided in the community, we observed a decrease in the number of important healthcare service parameters.

Conclusions and Impact

This study has shown significant improvements in important supportive care outcomes in association with the receipt of specialized community-based oncology nursing. In addition, the study's results also provide a rare longitudinal view of the experiences of patients living in the community with cancer, many of whom were in the later stages of illness. These are the first patient supportive care outcomes that we are aware of that have been measured in relationship to a specific supportive care intervention and occurring under usual current health system conditions. An important observation worth noting is that the *Interlink* intervention, as delivered in this study, was relatively simple and not resource intensive. For the majority of patients it involved an initial assessment followed by one or two home visits and an average of four phone contacts. Such information will be useful to other jurisdictions considering such a model.

These findings should be of particular interest to the Ontario Ministry of Health and Long-Term Care given the paucity of patient supportive care outcomes data that is available to decision makers and the ongoing mandate of Cancer Care Ontario and the MOH and LTC in addressing the supportive care needs of patients. Taken in combination with our previous research and the work of others in Canada and internationally, we feel that this study provides important evidence to support the positive effects of community-based specialized oncology nursing on important patient outcomes and resource utilization. The empirical evidence summarized in this report informs policy concerning the role of specialized oncology nursing as well as demonstrating the challenges in measuring patient derived supportive care outcomes when evaluating interventions.

Introduction

Background

The importance of providing coordination and supportive care services for cancer patients whose needs are frequently complex has widespread acceptance in our current health care system (Lauria, 1991). Unfortunately, supportive cancer care (SCC) in Ontario remains problematic due to the fragmentation of services that result in discontinuities of care for patients, and ultimately in unmet supportive care needs (Canadian Cancer Society, 2003) for patients and their families. This problem is especially evident in the community setting as described in the Ontario Cancer Plan 2005-2008, recently released by Cancer Care Ontario (CCO, 2006). It states:

“Too many patients experience a fragmented system with major gaps in supportive care, palliative care, health information and access to services”.

Ideally a comprehensive cancer care system will include coordinated supportive cancer care services that are designed to meet the physical, informational, emotional, psychological, social, spiritual and practical needs of people living with or affected by cancer (Cancer Quality Council of Ontario, 2003). However, regardless of projected increases in cancer incidence and prevalence (World Health Organization, 2002), the Ontario health care system has long been recognized as struggling to meet existing supportive care needs (Cancer Services Implementation Committee, 2001). Until recently, system integration initiatives continued to focus on targeting access to the medical therapies of cancer (surgery, systemic therapy and radiation therapy), driven in a large part by the concern over waiting times for these therapies. Although it is without dispute that timely access to medical care for cancer patients is a top priority, patients continue to describe significant unmet needs that are due to fragmentation and a lack of coordination of supportive care in the communities where they live. Our group investigated this in detail in a study, *Coordinating Supportive Cancer Care in the Community* (Brazil et al., 2003), which examined SCC at a system level. In this study we described the current lack of coordinated care more precisely. Gaps in provision of coordinated care existed at both the administrative and operational level, impacting comprehensiveness of care, accessibility of care, and the compatibility of different services available. Using the empirical data collected and analyzed in this study, the

research team proposed models based on evidence generated from data in Ontario to address the gaps that patient's experience. It was concluded that successful models must include interventions targeted not only at the administrative level of service provision but also directly at the operational or patient care level. Further, we concluded that a lack of designated community-based SCC coordination function was a significant contributor to frequently reported discontinuities in service provision and unmet patient supportive care needs.

A key finding of the coordination study was the identification of three supportive cancer care service delivery programs within the province directed at the patient level. Only one, *Interlink Community Cancer Nurses (Interlink)* was well established and provided coordinated care across the entire continuum. There is now accumulating evidence of the potential benefits of specialized nursing care models in the care of complex chronic diseases such as diabetes mellitus (Gabbay et al., 2006) and heart disease (Dunagan et al., 2005; Koelling et al., 2005; Riegel et al., 2005; Blue et al., 2001) and more recently, cancer (Wells et al., 2004; Bailey et al., 2004; Yates et al., 2005; Moore et al., 2002). Recently published studies of the impact of specialized nursing coordination have reported improvements in medical management of chronic disease parameters, improvements in knowledge and self-management, reductions in complications, improved satisfaction with care, and a reduction in the use of acute care services (Riegel et al., 2002).

In interpreting these types of studies it is important to note that the specifics of how the nursing care was deployed was tailored to the health system in which the program operated and the specifics of the disease under study (Bryant-Lukosius et al., 2004; Corner, 2003). It is clear in reviewing these studies that although they are supportive of the concept of the potential benefits of nursing coordination, the results are specific to a narrow set of conditions and may not be transferable between different complex chronic disease models. Thus prior to evaluating patient supportive cancer care outcomes, our group recognized the importance of having context specific empirical data upon which to categorize the characteristics of a community-based specialized oncology nursing model of supportive cancer care in Ontario. A study to better understand the processes of care necessary to meet the supportive care needs of cancer patients” *An Evaluation of the Effectiveness of a Specialized Nursing Case Management Program in Coordinating*

Supportive Cancer Care in the Community (Sussman et al., 2004)” was completed in 2004. This study provided a detailed description of *Interlink* as an example of such a model of care. In addition, the question of whether the program/model had the potential to coordinate supportive cancer care services, as defined by a specified theory of coordination was addressed. The model represented by the *Interlink* program, demonstrated the potential to enhance the coordination of community-based supportive cancer care service delivery and thus reduce the discontinuities experienced by patients (Brazil et al., 2004) and their families by “creating a system of support around the patient and family”. Whether this translated into improved patient supportive care outcomes remained unknown. A systematic literature review that was conducted as part of this project, demonstrated the important patient supportive care outcomes to examine including: measures of supportive care needs, quality of life, continuity of care and utilization of health services.

The current study aims to address the following objectives and questions:

Research Objective:

To evaluate the effectiveness of a specialized oncology nursing case management model in improving supportive cancer care outcomes for patients in the community.

Research Question

Do patients who receive care by an Interlink nurse have: (1) a reduction in unmet supportive care needs; (2) an improvement in quality of life; (3) improvements in continuity of supportive care; and (4) What is the pattern of health services utilization in a cohort of patients who receive specialized oncology nursing?

Study Methods

Study Design

The study is a repeated measure, longitudinal cohort design with patient outcome assessment at three intervals – baseline (T1), four (T2), and eight (T3) weeks. Trained interviewers collected data via telephone interviews using a standardized approach and validated instruments.

Study Population

Participants consisted of all referrals made to the Interlink adult program, which met the study inclusion criteria, from August 2004 to March 2005, and September 2005 to March 2006. These individuals were adults diagnosed with cancer who sought supportive care through self, family, or third party referral. Inclusion required respondents to be: physically capable to complete the interview, mentally competent, able to speak English, have a diagnosis of cancer, reside within the Interlink catchment area, and have no previous service relationship with Interlink. Participants were residents of the Greater Toronto Area (GTA), Ontario.

Study Intervention

In the spring/summer of 2005 the service unit, previously known as *Interlink Community Cancer Nurses*, transitioned to the *Community Interlink Program (Interlink)*. However, the program itself remained unchanged with respect to: its' "independent specialized nursing model" (Sussman et al., 2004), the nursing staff and the geographic coverage of the service. Prior to March 2005, *Interlink* was managed independently. In September 2005 *Interlink* came under the management of the Princess Margaret Hospital. During the transition there were no new patient contacts. The research study was temporarily suspended during this period. The transition also required applying for new REB approval at the University Health Network, the new host institution.

Interlink is a unique, specialized oncology nursing model that has existed as a community-based patient program in the GTA for a number of years. The nurses provide supportive cancer care in the community to a varied population at all points in the cancer continuum. The *Interlink* nurse will provide direct care in terms of information, emotional

support and limited physical care. One of the chief roles is to assess patients' supportive care needs and coordinate for the provision of other supportive care services available in the community, i.e., meals on wheels, professional counseling, etc.

Study Instruments

To assess the range of respondent supportive care outcomes, a battery of survey questions were compiled from established instruments. In addition to instruments assessing supportive cancer needs, quality of life, continuity of care, and service utilization, the study survey included questions about respondent demographics and current cancer treatment. The instruments underwent some modifications to tailor them to the population/setting of interest. The eight-week assessment included an open-ended qualitative question asking respondents to elaborate on their supportive cancer care experiences.

Demographics

Respondent demographics and characteristics of their cancer diagnosis were collected from two sources. For those respondents accrued during the August 2004 – March 2005 time frame, baseline demographics were obtained from the Interlink patient record database. For those respondents accrued during the September 2005 to February 2006 time period, the respondent provided their demographic information directly at Baseline (T1) at the request of the local REB. Those demographic variables that were common to both sources of data are listed in Table 1.

Table 1: Respondent demographics and diagnosis

From respondent	From Interlink database
<ul style="list-style-type: none">• Interlink nurse home visit or contact and date• Initial cancer diagnosis site and year of diagnosis• Cancer treatments• Household size• Marital status• Education• Household income	<ul style="list-style-type: none">• Age• Gender• Stage of Disease

Supportive Cancer Needs

The *Supportive Cancer Needs Survey Short Form 34* (SCNS-SF34) (Bonevski et al., 2000; Sanson-Fisher et al., 2000) was used to measure respondents' need for cancer support and care. This instrument captures needs through 34 items that cover five domains of supportive cancer care: Psychological Needs; Health System and Information Needs (related to treatment centre and information about the disease, diagnosis, treatments, and follow-up); Physical and Daily Living Needs (related to coping with physical symptoms, side effects of treatment, and performing usual tasks and activities); Patient Care and Support Needs (related to health care providers showing sensitivity to physical and emotional needs, privacy, and choice); and Sexuality Needs.

Each item is scored on a five point Likert scale (1=*not applicable*, 2=*need met*, 3=*low need remaining*, 4=*moderate need remaining*, 5=*high need remaining*), with overall higher scores denoting more needs that are not met. The instrument is consistent with Cancer Care Ontario Supportive Care policy documents and constructs within the Ontario supportive cancer care context.

Quality of Life

The *European Organization for Research and Treatment of Cancer QLC 30 version 3* (EORTC QLC-30_(v3)) was adopted to measure quality of life and functionality (Aaronson et al., 1993), and is one of the most commonly used quality of life instruments in oncology trials for measuring these aspects in cancer. The EORTC QLC-30_(v3) is a 30 item questionnaire incorporating 9 multi-item symptom factors (to capture the most common symptoms of cancer patients) and 5 functional factors scored on four point Likert scales (from 1=*not at all* to 4=*very much*), as well as a global health/quality of life factor (scored on a seven point scale ranging from 1=*very poor* to 7=*excellent*). Higher scores on the symptom factors indicate greater difficulty with these aspects of health. Higher scores on the functional factors (polarity reversed) and the global factor indicate better functionality and quality of life, respectively.

Continuity of Care

To measure continuity of care, we used the *Continuity and Coordination of Care Questionnaire* (CCCQ) (Booth et al., 2001; Velikova, 2003), adapted specifically for an

oncology setting from the *Components of Primary Care Index* (CPCI) (Flocke, 1997). The CCCQ instrument has 21 items scored on five point Likert scales (from 1=*strongly agree* to 5=*strongly disagree*), the higher score representing higher perceived continuity. Respondents are asked to rank their experience on three main aspects of continuity of care. These aspects are comparable to the key continuity constructs presented in an overview of the literature by Haggerty, Reid & McKendry (2002): usual practitioner (relational continuity), communication and knowledge (informational continuity), and coordination of care and accumulated knowledge (management continuity), as well as preference for having the same health care provider. At four weeks and eight weeks respondents were asked if they felt that the Interlink nurse had helped them with each original item on the questionnaire (yes/no).

Service Utilization

Actual use of supportive cancer care services by cancer patients is not well documented. As a secondary outcome we measured service utilization. An instrument, tailored to this study, was developed. To ensure that a broad enough scope of potential services was captured, this inventory was derived from Interlink referral data and a review of service utilization instruments used in previous studies (Brazil et al., 2003a; 2003b; Sussman et al., 2004). Twenty-four service types were grouped into seven categories: Physicians; Institutional/Hospital Programs; Nursing, Allied Health and Homemaker Support Programs; Social Support Program; Medical Supply Programs, and Community Support Programs. Participants were asked to indicate: which services were used in the past four weeks, frequency of use, and scheduled or urgent use.

Data Collection Procedure

Prior to study commencement a full day of interviewer training was conducted to orient three experienced interviewers to the study instruments, the consenting, and accrual processes. Prior to September 2005, the study protocol and data collection procedures were reviewed with one interviewer who had participated in the earlier phase of the study.

Between August 2004 and March 2005 data were collected from respondents in accordance with the McMaster University policy statement for research involving human

participants. In September 2005, *Interlink* administration transferred to Princess Margaret Hospital. This resulted in a short hiatus in patient accruals as the new administration was organized and it necessitated obtaining Research Ethics Board approval from the University Health Network (UHN). Service provision within the *Interlink* program remained unchanged.

Program personnel introduced all newly referred patients to the study at the time of intake. To support timely enrolment, permission was obtained from the patients to forward their contact information to study personnel. If amenable, a study package was sent to the potential participant and a research interviewer made telephone contact to discuss the study and obtain informed consent.

Inclusion and exclusion criteria were applied at the time of study introduction. The *Interlink* nurses screened potential participants for study eligibility.

The study package contained a list of the survey questions and a study information and consent form. The latter was to be completed by the participant after the interviewer explained the study and completed the informed consent process with them. Baseline (T1) responses were sought immediately upon consenting to participate in the study. The order and times at which study instruments were applied are indicated in Table 2.

Table 2: Survey instrument schedule

Baseline (T1)	4 Weeks (T2)	8 Weeks (T3)
Respondent's demographics and current treatment	Respondent's current treatment	Respondent's current treatment
Supportive Cancer Needs Survey	Supportive Cancer Needs Survey	Supportive Cancer Needs Survey
EORTC	EORTC	EORTC
Continuity of Care	Continuity of Care + ICCN Helped Question	Continuity of Care + ICCN Helped Question
Utilization Survey		Utilization Survey

Interlink Nurse Contacts with Patients

For those respondents who were recruited to the study between August 2004 and March 2005, a chart abstraction was done by the study's research coordinators to determine the number of home visits and direct telephone contacts made by Interlink Nurses to the respondents in this study between intake into the program and the second survey (T2) at four weeks.

For those respondents who were recruited to the study between September 2005 and March 2006, the nurses were asked to keep a 'Patient Contact Report Form' upon which they recorded: date of first phone contact, first home visit and then subsequent phone and face-to-face contacts during the time that the respondent was actively involved in the study.

Data Analysis Procedure

Response data were imported into and analyzed using SPSS version 13. The data obtained was summarized using descriptive statistical measures. Baseline demographics are reported for all respondents completing a baseline assessment (T1). Longitudinal analysis was on those individuals who had completed all three assessments (T1, T2 and T3). Change over time was measured using a repeated measures statistical analysis. To determine if there might be major differences between those who have not completed all assessments and those who did, demographic and baseline needs scores were examined.

The *Primary* study outcome was: change in respondent unmet supportive care needs from baseline (T1) to four (T2) and eight (T3) weeks. The *Secondary* study outcomes were: respondent quality of life, continuity of care, and use of health care related resources.

SCNS, EORTC, and CCCQ

Data collected from the SCNS, EORTC, and CCCQ were analyzed according to the guidelines of the validated instruments (Booth et al., 2001; European Organization for Research and Treatment of Cancer, 2004; McElduff et al., 2004; Velikova, 2003). Scores were calculated for specified domains within each of these instruments (see Appendix 1). For those respondents who completed all three interviews, comparisons between

baseline (T1), T2 and T3 were made using a non-parametric repeated measures ANOVA, “Freidman’s Test” as the repeated measures procedure.

Responses to the SCNS and CCCQ were expressed as mean values. Responses to the EORTC items were converted to standardized scores. Missing data were dealt with according to manual guidelines; if at least half of the items for a domain had been answered, it was assumed that the missing items had values equal to the average of those items that *were* present for that respondent.

For the SCNS instrument, responses of “1” or “2” on the scale represent *no need*, with 1 = not applicable and 2 = need met. To eliminate any difference observed between scores of 1 or 2 on the scale and produce a more conservative estimate of change, all responses of “1” on to this instrument were converted to “2”. This, in effect, created a four-point scale. The creators of the SCNS approved this conversion. To calculate the dichotomized high/low need values, SCNS factor scores were calculated for each individual respondent. Domain scores ranging from 1 to 3.49 are considered “low need” while a score ranging from 3.50 to 5 is considered “high need”. This classification is done according to specified SCNS guidelines.

Service Utilization

Service utilization was considered for 24 types of services organized within 7 categories: Physicians; Institutional/Hospital Programs; Nursing, Allied Health, and Homemaker Support Programs; Medical Supply Programs; Community Support Programs, and Service Coordination. As indicated in Table 2, data were collected from this instrument at baseline (T1), and at eight weeks (T3). Respondents were asked to recall which services they had used during the 4 weeks prior to the interview date. Service utilization is presented for respondents who were able to complete all three interviews. A descriptive reporting of service utilization is provided that identifies the number of respondents to report a particular service use and the corresponding proportions for T1 and T3.

Study Administration

Three meetings were convened with the Adult Program and administrative staff of *Interlink*. The first meeting was used to present the results of the program evaluation and

to introduce the next step, the patient outcome study. The second and third meetings oriented the staff to the process of patient recruitment and accrual at the beginning of each of the two study phases. Ongoing communication between the nurses, the study interviewer and the research coordinator worked toward maintaining reliable and rigorous processes of participant recruitment, accrual and tracking.

Study Results

Patient Accrual and Participation

A total of 368 patients were referred to Interlink from August 2004 to March 2005 and 192 patients were referred between September 2005 and March 2006. A combined total of 560 patients were referred to the Interlink Program during the study period. Baseline (T1) interviews were completed for 109 respondents. Of the admissions to the program, non-participants were categorized as follows (See Table 3): 177 patients were ineligible and 211 patients were classified as refusals.

At the time of writing, 109 participants have completed Baseline (T1) surveys, 86 have completed T2 surveys and 72 have completed T3. All outcomes data represent responses from the 72 participants who completed the study instruments at all three points in time.

Throughout the study period, accrual was lower than expected, primarily due to ineligibility (n=177) and refusal (n=211). Many patients were unable to participate due to illness. Although the interviewers (available at night and weekends) were completely flexible in conducting interviews at the respondents' convenience, scheduling interview times was challenging due to respondents' poor health and unstable condition.

Table 3: Patient ineligible/refusal/withdrawal to participate in study (N = 405)

	Frequency (%)
Ineligibility Criteria	N = 177
Inability to communicate	72 (40.7)
Incapable due to illness	24 (13.6)
Deceased	40 (22.6)
Prior patient of Interlink	13 (7.3)
No cancer diagnosis	3 (1.7)
Immediate discharge from Interlink (no service provided)	9 (5.1)
Patient refused Interlink service	16 (9.0)
Refusal Criteria	N= 211
No reason given by patient	111 (52.6)
Physical incapacity	67 (31.8)
Mental /emotional overburdened	19 (9.0)
Unable to Contact	14 (6.6)
Withdrawal*	17

Participant Demographics

The characteristics of the 109 respondents enrolled in the study and those who completed all three scheduled interviews are presented in Table 4.

Table 4: Respondent demographic characteristics

Characteristic	All respondents N = 109 (%)	Have T1, T2 and T3 finished respondents N = 72 (%)
Gender		
Male	30 (27.5)	17 (23.6)
Female	79 (72.5)	55 (76.4)
Age (yrs)		
20-49	21 (19.3)	12 (18.1)
50-69	64 (58.7)	47 (65.3)
70-79	14 (12.8)	7 (9.7)
80+	8 (7.3)	4 (5.6)
Missing	2 (1.8)	1 (1.4)
Household Size		
1 person	34 (31.2)	21 (29.2)
2 persons	45 (41.3)	35 (48.6)
3 persons	16 (14.7)	8 (11.1)
4 or more persons	14 (12.8)	8 (11.1)
Marital Status		
Single	16 (14.7)	13 (18.1)
Divorced/separated	27 (24.8)	18 (25.0)
Married/common law	53 (48.6)	34 (47.2)
Widowed	13 (11.9)	7 (9.7)
Education		
8 th grade or less	3 (2.8)	1 (1.4)
Some high school	9 (8.3)	6 (8.3)
High school diploma	19 (17.4)	13 (18.1)
Some college/university	10 (9.2)	6 (8.3)
College/university degree	54 (49.5)	34 (47.2)
Post graduated degree	13 (11.9)	11 (15.3)
Missing	1 (0.9)	1 (1.4)
Household Income		
Less than \$11,999	9 (8.3)	5 (5.9)
\$12,000 to \$19,999	14 (12.8)	9 (12.5)
\$20,000 to \$29,999	7 (6.4)	5 (6.9)
\$30,000 to \$49,999	16 (14.7)	9 (12.5)
\$50,000 to \$79,999	10 (9.2)	8 (11.1)
\$80,000 or more	22 (20.2)	16 (22.2)
Missing	31 (28.4)	20 (27.8)

In both the general study population and the sub-population that completed the protocol, the majority of these respondents were female (72.5) and between 50 and 69 years of age, with the median age being 59 years. Just over half of the groups (51.4) reported being single, divorced or widowed. Somewhat less than one-third (31.2) of respondents reported living alone. The group was relatively well educated with 89% reporting having at least graduated from high school. Almost half reported having graduated from college or university. Self-reported income levels varied. About one quarter of those who answered this question reported an annual household income below \$30,000, while 20% reported annual incomes of \$80,000 or more.

Participant Disease and Treatment Characteristics

The disease characteristics of the study population are presented in Table 5. For the purposes of this report, diagnoses that were reported were grouped into major disease site categories. The most commonly reported diagnosis was breast cancer with 32 respondents, followed by gastrointestinal (20) and lung (16) cancers.

Stage information was available for patients enrolled in the *Interlink Community Care Nursing Program*. Almost 50% had advanced disease. Following transition to the *Community Interlink Program* staging information was not available. Information regarding current medical treatment and time from diagnosis however, suggests that about 50% of patients continue to have advanced disease. Approximately 50% of patients were 6 months beyond diagnosis and receiving chemotherapy.

Table 5: Disease & Treatment Characteristics

Characteristic	All respondents N = 109 (%)	Have T1, T2 and T3 finished respondents N = 72 (%)
Major Disease Site Categories		
Breast	32 (29.4)	24 (33.3)
Gastrointestinal	20 (18.3)	13 (18.1)
Lung	16 (14.7)	10 (13.9)
Other	14 (12.8)	5 (6.9)
Hematology	10 (9.2)	6 (8.3)
Ovarian	8 (7.3)	7 (9.7)
Head & Neck	7 (6.4)	6 (8.3)
Prostrate	1 (0.9)	1 (1.4)
Missing	1 (0.9)	0 (0.0)
Stage of Disease**		
Advanced	18 (47.4)	16 (47.1)
Early Stage	20 (52.6)	18 (52.9)
Missing	73	38
Primary Treatment at Baseline (T1)		
No treatment	43 (39.4)	26 (36.1)
Chemotherapy	43 (39.4)	31 (43.1)
Other drug	11 (10.1)	6 (8.3)
Hormonal treatment	3 (2.8)	1 (1.4)
Radiotherapy	1 (0.9)	1 (1.4)
Unknown	8 (7.3)	7 (9.7)
Time from Diagnosis		
<= 180 days	52 (51.0)	39 (54.2)
>180 and <= 360 days	16 (15.7)	12 (16.7)
>360 and <= 540 days	8 (7.8)	6 (8.3)
>540 and <=720 days	4 (3.9)	3 (4.2)
>720 days	22 (21.6)	12 (16.7)
Missing	7	0

** Note: Disease stage is missing from patients seen between Sept 2005 and March 2006 as REB has yet to provide permission for in-depth chart review.

Intervention

The number and time of nursing contacts were collected to better describe the intervention received. This information was obtained through two sources. During the first leg of respondent accrual a chart abstractions process was undertaken to determine frequency and type of nurse-patient contact. In the later study period the nurses were

asked to keep a log of the nurse-patient contacts on each respondent. Those participants who finished the complete battery of surveys received a total of 112 home visits with a mean of 1.7 home visits per participant. The same group received a total of 257 phone contacts with a mean of 3.9 phone contacts for each respondent.

Survey Responses

SCNS

The results of the SCNS are presented in Table 6a. In order to avoid “survivor bias”^{***(see note)}, results are reported only on the 72 participants who completed the survey at all three time periods. A reduction in mean respondent need scores was observed in all SCNS domains between baseline (T1) and four weeks (T2), and between four weeks (T2) and eight weeks (T3). Three of the five domains, psychological needs; health system and information needs, and respondent care and support needs, show statistically significant improvements in the level of respondent need reported.

*Tendency for outcomes to improve over time because ill patients drop out and no longer available to complete outcome measures.

Table 6a: Descriptive statistics for The Supportive Cancer Needs Survey (SCNS) with Friedman’s test results.

	N	Baseline (T1) Mean (SD)	4 weeks (T2) Mean (SD)	8 weeks (T3) Mean (SD)	Chi-Square	p Value
Psychological needs	72	3.21 (1.01)	2.96 (1.00)	2.83 (0.92)	6.64	0.036*
Health system and information needs	71	2.78 (0.88)	2.59 (0.95)	2.44 (0.83)	11.01	0.004*
Physical and daily living needs	72	3.04 (0.98)	2.78 (1.05)	2.70 (0.95)	5.64	0.060
Patient care and support needs	72	2.55 (0.94)	2.34 (0.90)	2.21 (0.78)	7.66	0.022*
Sexuality needs	71	1.99 (1.24)	1.97 (1.21)	1.77 (0.96)	4.76	0.093

* Statistically significant difference.

To explore whether there could be a systematic difference between those respondents who completed T1, T2 and T3 and those respondents who completed T1 and perhaps T2 but not T3, a t-test was used on baseline (T1) scores to compare. Table 6b shows that there was no significant difference detected between the two groups.

Table 6b: The Supportive Cancer Needs Survey (SCNS) t-test results - Actual Scores

	Completed T1, T2 and T3		Only T1 or/and T2		t	p value
	N	Mean (SD)	N	Mean (SD)		
Psychological needs	72	3.21 (1.01)	37	3.24 (1.05)	-0.15	0.882
Health system and information needs	72	2.80 (0.89)	37	2.71 (1.09)	0.46	0.646
Physical and daily living needs	72	3.04 (0.98)	37	3.37 (1.06)	-1.63	0.106
Patient care and support needs	72	2.55 (0.94)	37	2.46 (1.04)	0.46	0.648
Sexuality needs	71	1.99 (1.24)	37	2.19 (1.30)	-0.78	0.438

The SCNS scale responses were also dichotomized to high and low need, Table 6c. All domains showed a decrease in the number of respondents who were reporting high need from T1 to T2 and T2 to T3. *Psychological needs* and *Health system and information needs* were the two areas where the greatest decrease in the percentages of respondents reporting high need was observed, 15.2% and 13.9% respectively.

Table 6c: Descriptive statistics for The Supportive Cancer Needs Survey (SCNS) High-Low Scores

	Baseline (T1)		4 weeks (T2)		8 weeks (T3)	
	N	High needs (%)	N	High needs (%)	N	High needs (%)
Psychological needs	72	33 (45.8)	72	24 (33.3)	72	22 (30.6)
Health system and information needs	72	19 (26.4)	71	13 (18.3)	72	9 (12.5)
Physical and daily living needs	72	23 (31.9)	72	20 (27.8)	72	17 (23.6)
Patient care and support needs	72	14 (19.4)	72	7 (9.7)	72	7 (9.7)
Sexuality needs	71	11 (15.5)	72	9 (12.5)	72	7 (9.7)

As an exploratory analysis we used linear regression to look at factors (age, sex, disease site, time from diagnosis, and treatment) that may predict baseline needs and more importantly change in need over time associated with *Interlink* use. This analysis was restricted to the psychological and informational domains. While younger age ($p < .05$) predicted a higher need at baseline, no particular factors were associated with change in need over time indicating that improvements over time were seen for all subgroups both young and old, male and female etc.

EORTC

Table 7 shows the overall health status of respondents at baseline as relatively low on the EORTC Quality of Life instrument consistent with the advanced stage of disease of the participants. While there was little change over time, in general health status measures (e.g., global health status, physical functioning), improvement was seen in role functioning ($p < .05$). In addition the majority of symptom specific measures, (e.g., fatigue, pain, nausea and vomiting) tended to decrease over the study period.

Similar to the analysis done on the SCNS, a t-test was used on baseline (T1) scores to compare whether there could be a systematic difference between those respondents who completed T1, T2 and T3 and those respondents who completed T1 and perhaps T2 but not T3. No statistical differences were seen between the two groups.

Table 7: Friedman's test results for EORTC QLC-30

	N	Baseline (T1) Mean (SD)	4 weeks (T2) Mean (SD)	8 weeks (T3) Mean (SD)	Chi-Square	p Value
Global health status	72	53.5 (22.4)	50.3 (21.9)	52.7 (22.5)	1.66	0.436
Physical functioning	71	69.1 (19.7)	70.2 (20.2)	69.7 (22.0)	0.81	0.666
Role functioning	72	48.4 (28.4)	53.5 (34.6)	59.3 (28.6)	6.04	0.049*
Emotional functioning	72	64.7 (24.0)	62.2 (24.5)	61.2 (24.2)	1.54	0.464
Cognitive functioning	72	70.8 (23.9)	67.4 (24.0)	69.4 (23.2)	3.69	0.158
Social functioning	72	53.2 (31.6)	60.4 (33.7)	59.5 (33.7)	4.88	0.087
Fatigue	72	53.4 (23.8)	50.5 (25.3)	51.7 (25.2)	1.64	0.440
Nausea and vomiting	72	18.8 (24.2)	16.4 (24.0)	14.4 (21.9)	3.81	0.149
Pain	72	36.1 (31.5)	38.4 (35.3)	34.3 (31.6)	0.03	0.986
Dyspnoea	72	25.5 (29.3)	19.9 (27.8)	24.5 (25.6)	3.45	0.178
Insomnia	72	45.8 (32.8)	45.4 (38.1)	40.7 (36.4)	1.65	0.437
Appetite loss	71	30.0 (32.4)	28.6 (34.9)	24.9 (33.2)	3.57	0.168
Constipation	72	39.4 (36.0)	31.5 (34.0)	32.4 (34.0)	2.28	0.320
Diarrhoea	72	11.1 (20.2)	12.0 (21.9)	14.8 (26.8)	0.02	0.989
Financial difficulties	72	30.6 (39.1)	32.9 (38.1)	31.5 (36.2)	1.45	0.485

CCCQ

At baseline (T1), respondents reported, on average, a low level of perceived continuity for each of the instrument factors (see Table 8a). While trends in improvements in perceived continuity were seen in health care providers knowledge

about the patient; interpersonal communication; and patient preference, these did not reach statistical significance.

Table 8a: Friedman's test results for CCCQ

	N	Baseline (T1) Mean (SD)	4 weeks (T2) Mean (SD)	8 weeks (T3) Mean (SD)	Chi-Square	p Value
Health care providers' accumulated knowledge about the patient (Informational)	71	3.32 (0.88)	3.44 (0.90)	3.43 (0.89)	2.03	0.362
Coordination of care (Management)	71	3.51 (0.63)	3.58 (0.62)	3.48 (0.61)	1.97	0.374
Interpersonal communication (Relational)	71	3.55 (0.93)	3.66 (0.96)	3.64 (0.97)	4.97	0.084
Patient preference	72	3.43 (0.41)	3.53 (0.49)	3.56 (0.41)	2.97	0.226

Higher score represents higher perceived continuity

At T2 and T3 an additional question was added to the CCCQ instrument that invited the respondent to identify whether they found the involvement of the Interlink nurse to be helpful in relation to each of the instrument items. Table 8b shows the results of that question at T2. More than 50% of respondents reported the Interlink nurse being helpful in all survey items. Respondents reported the Interlink nurse to be especially helpful in two survey items. Eighty-three point three percent (83.3%) of respondents reported that they felt that the Interlink nurse helped in the area represented by “The health care providers clearly understand my supportive needs.” In the domain represented by “Sometimes the health care providers do not listen to me” 80.9% reported the Interlink nurse being helpful. In two items (#16 and #21) related to ease of communication, the Interlink nurse was perceived to be helpful by 69.4%.

Table 8b: Respondent’s self-reported experience of ICCN nurse’s helping with aspects of continuity of care at four weeks (T2). (N=72)

Question	Yes (%)	No (%)	Unknown (%)
1. The health care providers clearly understand my supportive needs	60 (83.3)	11 (15.3)	1 (1.4)
2. Sometimes the health care providers do not listen to me	58 (80.6)	14 (19.4)	0 (0.0)
3. I want one health care provider to arrange all the support I receive	44 (61.1)	25 (34.7)	3 (4.2)
4. The health care providers I see communicate with each other	37 (51.4)	31 (43.1)	4 (5.6)
5. (in general) I rarely see the same health care provider for a given problem or need	43 (59.7)	27 (37.5)	2 (2.8)
6. The health care providers do not always know my supportive need history and problems very well	45 (62.5)	27 (37.5)	0 (0.0)
7. The health care providers know the results of previous visits	39 (54.2)	31 (43.1)	2 (2.8)
8. My care improves when I see the same health care provider for a given problem or need	43 (59.7)	26 (36.1)	3 (4.2)
9. The health care providers always follow up on a problem I've had before	43 (59.7)	27 (37.5)	2 (2.8)
10. It is very important to me to see my regular health care providers (in team)	46 (63.9)	25 (34.7)	1 (1.4)
11. The health care providers know how I feel emotionally while they are treating me	46 (63.9)	26 (36.1)	0 (0.0)
12. The health care providers do not always know about the support and care I have received previously	36 (50.0)	32 (44.4)	4 (5.6)
13. I don't mind seeing different health care providers because everyone knows my case	36 (50.0)	32 (44.4)	4 (5.6)
14. The health care providers always explain things to my satisfaction	49 (68.1)	19 (26.4)	4 (5.6)
15. The health care providers I see know what my care plan is	40 (55.6)	29 (40.3)	3 (4.2)
16. I don't always feel comfortable asking the health care providers' questions	50 (69.4)	20 (27.8)	2 (2.8)
17. The health care providers know about personal things in my life (family, job, hobbies, social life)	38 (52.8)	32 (44.4)	2 (2.8)
18. I often have to repeat my problems to the different health care providers I see	41 (56.9)	27 (37.5)	4 (5.6)
19. I would rather wait for the health care provider who saw me last for a given problem or need than be seen by the next available health care provider	42 (58.3)	27 (37.5)	3 (4.2)
20. The health care providers usually know about the problems that have bothered me at previous visits	43 (59.7)	26 (36.1)	3 (4.2)
21. I can easily talk about personal things with the health care providers	50 (69.4)	19 (26.4)	3 (4.2)

Service Utilization

Table 9 presents respondent-reported service utilization for the time period four weeks prior to baseline (T1) and four week period prior to T3 completion. At baseline (T1) the most commonly reported single service type was *pharmacist*, used by 64 (89%) respondents. The *family doctor* was reported as being used by 55 (76%) respondents and the *oncologist* was reported as being used by 54 (75%) participants. The frequency

with which *surgeons* and *visiting nurses* were used was 32 (44%) and 30 (42%) respectively.

A shift in the service utilization pattern emerged in the T3 data. The use of health professionals decreased. The use of pharmacists decreased from 89% to 76% ($p < .05$), family physician contact decreased from 76% to 54% ($p = .005$) and surgeon contact decreased from 44% to 18% ($p = .001$). While the number of patients that used home nursing (including *Interlink*) did not decrease, the number of median visits decreased from 8 visits to 4 visits.

Acute care visits, especially hospital daycare, decreased from 11% to 1% ($p = .02$) and emergency visits decreased from 19% to 10%. The latter did not reach statistical significance.

Interesting trends were also seen in the decrease in the use of other allied health professionals (dietitians, physiotherapists and counseling). There was also a tendency for increasing use of self-help and support groups over time.

Table 10: Respondent reported frequency of each service type used (N=72)

Service type	Frequency using this service (%)		Median number of times used		Chi-Square*	p Value
	T1	T3	T1	T3		
Family doctor seen or telephoned	55 (76.4)	39 (54.2)	2.0	1.0	7.84	0.005 ⁺
Oncologist seen or telephoned	54 (75.0)	53 (73.6)	2.0	2.0	0.04	0.849
Surgeon seen or telephoned	32 (44.4)	13 (18.1)	2.0	1.0	11.67	0.001 ⁺
Any other medical specialist seen or telephoned (e.g., Urologist, Respiriologist, Radiotherapist, Psychiatrist, etc.)	25 (34.7)	21 (29.2)	1.0	1.0	0.51	0.475
Pharmacist	64 (88.9)	55 (76.4)	2.0	2.0	3.92	0.048 ⁺
Hospital emergency room	14 (19.4)	7 (9.7)	1.0	1.0	2.73	0.098
Hospital day surgery	8 (11.1)	1 (1.4)	1.0	1.0	5.81	0.016 ⁺
In-home nursing care (e.g., for changing dressings, checking blood pressure, etc.) Visiting nurse (less than 2 hours per visit)	30 (41.7)	30 (41.7)	8.0	4.0	0.00	1.000
Allied health care (e.g., Dietician, diabetic counselor, Chiropractor, Physiotherapist, Occupational therapist, etc.)	19 (26.4)	14 (19.4)	3.0	3.0	0.98	0.322
Personal support / Homemaker support	16 (22.2)	19 (26.4)	4.0	4.0	0.34	0.560
Professional counselling (e.g., Social worker, Psychologist, etc)	23 (31.9)	19 (26.4)	2.0	1.0	0.54	0.463
Self-help or support groups (e.g., Wellspring cancer support, Cancer Connection, Gilda's Club, etc.)	16 (22.2)	22 (30.6)	1.0	3.5	1.29	0.257
Spiritual support (e.g., Minister, Priest, Rabbi, Imam, etc.)	19 (26.4)	19 (26.4)	2.0	1.5	0.00	1.000
Transportation service (e.g., Volunteer drivers, WheelTrans, etc.)	10 (13.9)	10 (13.9)	2.5	1.0	0.00	1.000
Information supports (e.g., cancer clinic library, community resource centre, Canadian Cancer Society, etc.)	20 (27.8)	14 (19.4)	1.0	4.0	1.39	0.239
Financial counselling or assistance programs (e.g., social assistance, Ontario Drug benefits, Trillium, etc.)	11 (15.3)	9 (12.5)	1.0	1.0	0.23	0.630
Legal counselling	4 (5.6)	5 (6.9)	2.0	2.0	0.12	0.731
Home delivered meals (e.g., Meals on Wheels, etc.)	4 (5.6)	9 (12.5)	4.5	4.0	2.11	0.146
Community Care Access Centre (CCAC) Case Manager	14 (19.4)	12 (16.7)	1.0	1.5	0.16	0.693
Other services not mentioned	43 (59.7)	37 (51.4)	1.0	1.0	1.01	0.314

* Chi Square compares proportions of patients in T1 vs T3 who reported using the service

+ p-value significant

Discussion

Despite efforts to address the supportive care needs of cancer patients, studies in Ontario continue to demonstrate unmet supportive care needs for patients and their families primarily due to the fragmentation and poor coordination of current services (Canadian Cancer Society, 2003; Cancer Quality Council of Ontario, 2003; Cancer Care Ontario, 2005). Similar observations have been made in other jurisdictions in Canada and Australia (Aranda, 2005). Recent research has demonstrated that specialized nursing care models in the care of complex chronic diseases can result in improvement in the management of chronic disease parameters with an increase in patient knowledge, self management, and a reduction in symptoms and the use of acute care services. A previous study by the SCCR Unit commissioned by the Ontario MOH & LTC suggested that a specialized oncology nursing program, based in the community, had the potential to provide immediate direct services and enhance the coordination of community based supportive cancer care, thus reducing the discontinuities experienced by patients and their families. The purpose of this study was to evaluate the longitudinal impact of such a program on cancer patient outcomes. This was a unique study attempting to address key supportive care needs of patients many of whom were at an advanced stage in their disease trajectory. The patients included in this study were assessed at the time of initial contact with the nursing program, at 4 weeks and 8 weeks. Our results provide an important profile of the needs, quality of life, continuity of care and patterns of health services utilization over time in a group of cancer patients representing the broad spectrum of the cancer experience in the community.

Key Findings

The most important finding of this study is the confirmation of our hypothesis that patients who receive specialized oncology nursing will have improvements in the most important supportive cancer care outcome, having their needs met across the spectrum of supportive care domains. Patients' need for psychological support, informational needs, daily living, patient care and support needs were compared to baseline at 4 weeks and 8 weeks following introduction of *Interlink* care. A significant reduction in

patients' unmet needs for psychological support, informational needs, and patient care were seen at 4 weeks, which continued to improve at 8 weeks. The need for physical support and daily living also continued to improve and bordered on statistical significance. It was estimated that as many as 10-15% of patients experienced improvements in these domains. No baseline variables such as age, sex, disease site, or time from diagnosis, were associated with greater or lesser improvement in needs suggesting that all sub groups of patients benefited from the nursing intervention.

In addition to the impact on patient supportive care needs important changes were also observed in patients' quality of life. Although no improvement was observed in patients' global health or physical functioning, no deterioration was seen. This is an important observation as the expectation with such an advanced disease population is steady deterioration in quality of life over time as suggested by a number of studies (Peters & Sellick, 2006; Grunfeld, 1999). In addition, patients' physical role functioning improved over the 8 week period and important trends were seen in social functioning. Consistent with the improvement in role functioning patients' symptoms, in particular fatigue, nausea, vomiting, pain, insomnia, appetite loss, and constipation all decreased over the 8-week period. These observations are consistent with the meeting of patients' needs and the support that they received from the *Interlink* nursing program.

While the study did not demonstrate a dramatic improvement in the continuity of care over time, important trends were observed in health care providers knowledge about the patient, interpersonal communication and support of patient preferences. Such improvement can be attributed to the *Interlink* nurse given that over 50% of respondents reported that the nurse was helpful in all continuity of care items and in particular in relation to supportive care needs and communication, where the nurse was identified as helpful in over 70% of respondents.

The corresponding data on service utilization is particularly interesting. Normally the introduction of supportive care interventions can often result in a paradoxical increase in use of healthcare resources. In our previous study where patients with advanced breast cancer were offered early referral to community care access centres, the number of acute-care encounters significantly increased (Grunfeld, 1999). In the current study of this specialized nursing oncology program, which provides some direct care services

and coordinates other services provided in the community, we observed a decrease in the number of important healthcare service parameters. In particular physician contact, either surgeon or family physician, decreased from 22-26% over the course of the study. Of note, no increase was seen for other specialties. In addition, in terms of other health professionals, pharmacist contact decreased and trends were observed for other professional services including dietitians, physiotherapists, and counseling. In contrast for home nursing care and visiting nurses (including *Interlink*), no increases were observed and the median number of visits decreased from 8 to 4. Of particular note, acute hospital encounters such as day care decreased significantly (from 11% to 1%) and important trends were observed for a reduction in emergency visits from 19% to 10%. Of interest, trends were seen for an increase in utilization for certain services such as self-help and support groups and home delivered meals which would be likely to have a limited financial impact. While this data is intriguing it is important to note that the time period involved was relatively short (3 months) and this study did not have a concurrent non-treated control and it is unclear if some of these changes may be related to the course of illness.

Study Attributes

This was a challenging study to complete as the majority of patients were ill or in the advanced stages of disease and had increased supportive care needs. The relatively straightforward design of this study facilitated successful accrual in a setting (community) and population (cancer patients who were quite unwell, as reflected in baseline quality of life scoring) that are rarely described or studied in detail and in sufficient numbers. The complexities and barriers to completing studies in these settings are well documented in published literature (McWhinney, Bass & Donner, 1994). Two challenges that faced the research team were: (1) the complexities of introducing study specific processes in tandem with the administrative and care provision processes of the program and to ensure minimal impact on these; and (2) the collection of a large amount of information from a population that is unwell and dealing with the consequences of cancer and its treatments. Although in some cases we were unable to obtain baseline

measures prior to first patient contact with the nurse, in all instances, these were obtained within short time of initial contact. The probable effects on study outcomes are felt to be negligible and if anything there could be an attenuation of the changes seen in the main study outcome (unmet needs) and it is possible that our findings could be an underestimate of the true changes over time.

To minimize the effect of “survivor bias” due to dropouts and lost data, the longitudinal analysis involved only those patients who completed all study measures. It is important to note that baseline needs scores for the 72 patients in this group did not differ significantly from the needs scores of the 37 patients who did not complete all study measures. It is also acknowledged that some patients who dropped out may have had worse scores than those who did not drop out and therefore losing their data would lead to an overestimate of measures at 4 and 8 weeks. We propose that this is a reflection of what happens under typical clinical conditions and the findings of this study are a reflection of what truly occurs within the current care conditions and system of care in Ontario.

Although accrual to the study has been lower than predicted, the baseline demographic characteristics suggest that participants are a valid representation of the population served by the program, namely patients living with cancer in the community who are served by the community-based, specialist oncology nursing program. It is hypothesized that these patients have higher needs than the general oncology population at any given point in the supportive care trajectory, based on the fact that they were referred to the nursing program to address issues that were likely not being effectively managed in the cancer care system. Our accrual is consistent with other population based studies of cancer patients especially in unwell/palliative populations, where the intensity of measures is perceived to be an excessive burden leading to refusal (Gunn et al., 1999; Cohen et al., 1997) and drop-outs are high due to the natural history of the illness over the study period.

An important observation worth noting is that the *Interlink* intervention, as delivered in this study, was relatively simple and not resource intensive. For the majority of patients it involved an initial assessment followed by one or two home visits and an

average of four phone contacts. Such information will be useful to other jurisdictions considering such a model.

Study Limitations

It is important to note that the requirements of the current study resulted in a number of limitations. Language and communication issues lead to a significant number of exclusions, as did the category of *ineligibility due to illness* (and thus excessive burden from participation or inability to complete all study measures). These issues do have implications for the generalizability of the findings especially in culturally diverse regions such as the Greater Toronto Area. Subsequent studies will need to address cultural diversity, as the spectrum of issues, experiences, and needs of non-English speaking patients and their families are likely to be different from those who can communicate in English.

Despite the fact that we did demonstrate marked improvement in unmet supportive care needs, changes in quality of life and the continuity of care were less dramatic. The EORTC QLC 30 was developed primarily to assess the impact of cancer treatment on patients quality of life so physical symptom items reflective of chemotherapy and radiation are well represented and other items reflective of the impact on emotional well being, social functioning and activities of daily living less so. Despite these limitations we did see some effect of the specialized nursing care intervention on role and social functioning.

A similar sets of issues, relate to the continuity of care instrument used in this study. While there have been many references to the importance of continuity in the care of cancer patients, there is unfortunately no gold standard of measurement in any setting. The continuity of care questionnaire developed for this study was primarily developed for a primary care setting it assumes one primary care provider and does not really capture the phenomena of multiple caregivers at any point in time. While this instrument was modified for this study it likely was not well adapted for the unique population studied. The low baseline scores that we identified are likely a reflection of the poor continuity of total care both medical and supportive care management that was experienced by the

respondents. Given that patients had many providers as described in the summary of utilization data, it is likely that the short time period and introduction of the *Interlink* nurse was not adequate to fully impact on continuity of care as measured in this study.

Summary

In summary, this study has shown significant improvements in important supportive care outcomes in association with the receipt of specialized community-based oncology nursing. These are the first patient supportive care outcomes that we are aware of that have been measured in relationship to a specific supportive care intervention and occurring under usual current health system conditions. The intervention as delivered was relatively simple and limited in nature with a limited number of home visits. This finding should be of particular interest to the Ontario Ministry of Health and Long-Term Care given the paucity of patient supportive care outcomes data that is available to decision makers and the ongoing mandate of Cancer Care Ontario and the MOH and LTC in addressing the supportive care needs of patients. Taken in combination with our previous research and the work of others in Canada and internationally, we feel that this study provides important evidence to support the positive effects of community-based specialized oncology nursing on important patient outcomes and resource utilization. The empirical evidence summarized in this report informs policy concerning the role of specialized oncology nursing as well as demonstrating the challenges in measuring patient derived supportive care outcomes when evaluating interventions. Given the potential limitations of an observational study design especially in estimating the degree of change in supportive care outcomes, further research is needed to more precisely define the extent of impact on supportive care outcomes using a randomized design. Such a study is currently underway with support from the Ontario MOH and LTC and has received partial funding from the Canadian Institutes of Health Research. This study will provide important information regarding the potential impact of specialized community-based oncology nursing in newly diagnosed patients. Future research is also needed to further define the concept and importance of continuity of care in the cancer population and optimization of the roles of the multiple providers involved in the care of these patients over the cancer care trajectory. This is an area of interest in the Supportive Cancer Care Research Unit specifically with regards to the evolving roles of community-

based (e.g., family physicians) and institutionally-based providers (e.g., oncologists) and ways to facilitate care continuity when the care trajectory involves multiple providers at any given point in time, potential role confusion and the likelihood of multiple care transitions.

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Appendix A: Instrument Factors

Supportive Cancer Needs: SCNS-SF34

Factor	Number of items	Item range	Item numbers
Psychological needs	10	4	6 to 14, 17
Health system and information needs	11	4	23 to 30, 32 to 34
Physical and daily living needs	5	4	1 to 5
Patient care and support needs	5	4	18 to 22
Sexuality needs	3	4	15, 16, 31

Quality of Life: EORTC QLC-30_(v3)

Factor	Number of items	Item range	Item numbers
Global health status / QoL	2	6	29, 30
Functional scales			
Physical functioning	5	3	1 to 5
Role functioning	2	3	6, 7
Emotional functioning	4	3	21 to 24
Cognitive functioning	2	3	20, 25
Social functioning	2	3	26, 27
Symptom scales / items			
Fatigue	3	3	10, 12, 18
Nausea and vomiting	2	3	14, 15
Pain	2	3	9, 19
Dyspnoea	1	3	8
Insomnia	1	3	11
Appetite loss	1	3	13
Constipation	1	3	16
Diarrhoea	1	3	17
Financial difficulties	1	3	28

Continuity of Care: CCCQ

Factor	Number of items	Item range	Item numbers
Health care providers' accumulated knowledge about the patient (Informational)	4	4	1, 6, 11, 17
Coordination of care (Management)	7	4	4, 7, 9, 12, 15, 18, 20
Interpersonal communication (Relational)	4	4	2, 14, 16, 21
Patient preference	6	4	3, 5, 8, 10, 13, 19

Note: the polarity of items 2, 5, 6, 12, 16, and 19 are reversed.