

Final Report

An Evaluation of the Effectiveness of a Specialized Nursing Case Management Model in Coordinating Supportive Cancer Care in the Community

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Executive Summary

Coordination of Supportive Cancer Care (SCC) in the province of Ontario remains problematic. In March 2003 the Supportive Cancer Care Research Unit submitted the results of the study “Coordinating Supportive Care in the Community” to the Ontario Ministry of Health and Long Term Care. This study led to recommendations for decision makers to consider at the administrative and operational levels of supportive care coordination. One of our key recommendations was to establish specialized supportive cancer care case managers. In May 2003, Dr. Les Levin, head of the Medical Advisory Secretariat of the Ontario Ministry of Health and Long Term Care, asked the Supportive Cancer Care Research Unit to undertake further study of specialized case management as a potential operational level solution to improve the coordination of supportive care. This report represents the results of the study.

The overall goal of this study was to evaluate the effectiveness of a specialized oncology nursing model in the coordination of community-based SCC. The specific study objectives were:

1. To study the effectiveness of specialized oncology case management in the coordination of supportive care of cancer patients as described in the published literature.
2. To develop an in-depth understanding of the *Interlink* cancer care nursing model and its coordination function at the operational and administrative levels.
3. To evaluate the model of community-based specialized nursing oncology case management as represented by *Interlink* cancer nursing for its potential as a program to facilitate the coordination of supportive care of cancer patients in the community.

This study has components to address each of the three objectives. To address Objective 1 we carried out a systematic review of the literature on the effectiveness of case management on patient and care system outcomes. To address Objective 2 we conducted an in depth case study of the *Interlink* Community Care Nurses (Interlink) program in the Greater Toronto Area. To address Objective 3 we used a criterion evaluation approach that compared data collected from the program and service partners with a set of measures that reflect coordination of care at the operational level.

A synthesis of the findings from all of these components has resulted in a set of recommendations to enhance the coordination of SCC services.

Method

Mixed methods were used to enable the investigative team to address each of the three identified study objectives. Data collection was carried out to address each study component using instruments and procedures that were pilot tested. Both quantitative and qualitative data were collected, appropriate to the issue being explored. The literature review involved standard procedures for inclusion criteria, study identification, data extraction, and summary of relevant findings. The setting for the study was the Greater Toronto Area. Data sources for the case study and criterion evaluation included Interlink program administrative data of 700 new admissions in the 2001-2002 year, surveys and face-to-face interviews of Interlink Nurses (6) and the Senior Administrator (1), surveys and telephone interviews of a purposive sample of service delivery partners that have worked with Interlink (27) and an in-depth review of 113 charts chosen to represent complex cases. All data was summarized using standard nomenclature appropriate to the data type. The framework to address Objective 3 was presented to a project consultation group for review and comment prior to the initiation of data collection.

Results

Objective 1

The systematic review of the literature (1993 to June 2003) yielded 1804 citations resulting in 16 unique studies. Most were non-randomized. Significant heterogeneity of interventions (including care contexts) and outcomes measured resulted in difficulties in interpretation. In general, patient satisfaction was high and positive effects were noted for targeted (i.e., symptom or disease specific) interventions. It also appeared that interventions at the earlier stage of the care trajectory may have the greatest effects.

Objective 2

Interlink was found to provide care to a varied population at all points in the cancer continuum. Care is provided within an independent practice model that is client centred. Most care was provided to patients in the later stages of the cancer care trajectory with needs identified in all domains of supportive care. Of the 700 admissions in the year of study, the mean number of face to face contacts with the program was two, with a mean of seven telephone contacts. Forty percent of new patients were in the program for two months or less with 74% of patients in the program for six months or less. The largest source of referral to the program was noted to be hospitals (35%) followed by self-referral (26%) and Community Care Access Centres (19%). Of the 34% of patients who had documentation of linkages made by the program to other providers, the majority were to non-institutional providers. Direct care provision by the *Interlink* program was in the emotional and informational supportive care domains with linkages to service providers to address other needs identified that could not be directly provided by the program. There were very short waiting times found for intake and assessment.

The nurses in the program all had advanced oncology training and oncology experience that ranged from 2 to 14 years. A logic model of structures and processes of care identified four major program components; Specialized Oncology Nursing and Supportive Care, Coordinated Mobilization and Linkage to Resources, Community-Based Education and Research, and Community Resource Development. Most attributes of case management were identified as part of the practice model, but it became apparent during the course of the study that the *Interlink* Model goes beyond a traditional case management approach to provide unrestricted care coordination driven by individual needs. There is no service brokering as part of the model. It was noted that ongoing development in evidence based care and quality assurance is needed.

Objective 3

The potential for the *Interlink* model to facilitate care coordination at the direct patient care level was assessed using a criterion evaluation approach that compared data collected from the program (including interviews with service partners) with measures of

the elements of coordination at this level; comprehensiveness, accessibility, and compatibility.

The observation was made that the program appears to build a system of care around a patient that is unique to their needs. Comprehensiveness of care was demonstrated by a high rate of assessment of needs in all domains of supportive care, as well as direct care and observations of patterns of referral to providers that could address any supportive care need. Limited evidence was also found to support program influence of the system of care by participating in activities to address care gaps and resource limitations. Accessibility was demonstrated by a lack of significant program barriers, short times to assessment from intake and processes to facilitate access to other care providers including monitoring of the referral process. Some limitations were noted by service partners, mostly in awareness of the program and perceptions of geographic boundaries that could potentially limit service availability. Compatibility was demonstrated by satisfaction with information exchange, little tension between Interlink and other service providers, and the client centred approach to care that is foundational to the *Interlink* approach and acknowledged by service provider partners. There was noted to be some confusion of roles by service partners in coordination activities when Interlink was involved. Information exchange could be further improved through written communication with service provider partners and sharing of the *Interlink* assessment.

The *Interlink* program is unique. This model appears to have the potential to reduce gaps in coordination of supportive cancer care at the operational level. The result of this study are important to decision-makers interested in improving supportive cancer care in the province of Ontario.

Recommendations

The findings of this study have led to a series of recommendations to be considered by decision makers based on our findings:

1. *Community based specialized nursing as represented by the Interlink nursing cancer care model should be considered for more wide spread deployment in the Province of Ontario as a direct patient care intervention to address regional gaps in coordination of supportive cancer care.*

If such a model is considered for more widespread deployment, policymakers will need to consider a number of prerequisites to ensure success and sustainability: 1) stable funding, 2) appropriate case loads, and 3) minimum standards for adequate training.

2. *The Interlink model should become more integrated with existing cancer and community care systems within each region.*
3. *The model should remain community based.*
4. *Further research should focus on patient supportive care outcomes.*

Chapter 1

Introduction

Background

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. This is especially true in the community setting. In our previous study, “Coordinating Supportive Cancer Care in the Community” (Brazil et al., 2003), we reported that supportive care is currently not well coordinated and that models of care that could address the gaps that patients experience must include interventions targeted not only at the administrative level but in addition directly at the operational or patient care level. One of our key recommendations was to establish specialized SCC case managers. We identified a number of key attributes necessary for such a model including: a client centered and evidence based approach; standardized, comprehensive, and continuous assessment; established links with other care providers; and promotion of continuing education and quality improvement. We suggested that a community based model that would

assess needs and provide or arrange for required care services in all supportive care domains was essential in addressing the SCC gaps which continue to be reported by patients and their families. Our findings suggested that there is currently no one practitioner or institution that is consistently identified as having a community based SCC coordination role in the province.

There have been attempts to address supportive care gaps through interventions targeted at the administrative level. In a research project to evaluate the development of Regional Supportive Care Networks (Whelan et al., 2003) we found that, to date, there has been limited success. While this is partly due to under-funding, it was mainly found to be due to a lack of operational coordination at the patient care level, reinforcing the need for interventions that target this level.

Although the rationale for specialized case management in the care of patients with chronic illnesses and complex needs such as cancer is compelling, high quality empirical data to support this approach remains limited

(Brazil et al., 2003). In fact, many policy papers still suggest a need for in-depth study of models in their specific health care contexts as being important for decision makers to consider prior to widespread deployment (Canadian Breast Cancer Initiative, 2002; Hollander & Prince, 2002; Hudson, 2001; Leatt, Pink, & Guerriere, 2000).

The Interlink Community Cancer Nurses (*Interlink*) is a unique specialized oncology nursing model that has existed as a community-based patient program in the Greater Toronto Area for a number of years. It has been suggested that such a model addresses the gaps in supportive care services reported by patients and their families at all points during the continuum of care (Howell, Fitch, & Caldwell, 2002). The Ontario Ministry of Health and Long Term Care (MOHLTC) commissioned the Supportive Cancer Care Research Unit (SCCR Unit) to study this model in more depth for its potential to improve coordination of SCC.

This report represents the result of an intense 10-month study to address the goals and objectives agreed upon by the investigative team and our MOHLTC research partners and ratified by a

project consultation group that included key stakeholder representation.

The overall goal of this study is to evaluate the effectiveness of a specialized oncology nursing model in the coordination of community-based SCC. The specific study objectives are:

1. To study the effectiveness of specialized oncology case management in the coordination of supportive care of cancer patients as described in the published literature.
2. To develop an in-depth understanding of the *Interlink* cancer care nursing model and its coordination function at the operational and administrative levels.
3. To evaluate the model of community-based specialized nursing oncology case management as represented by *Interlink* cancer nursing for its potential as a program to facilitate the coordination of supportive care of cancer patients in the community.

The report is organized to address each of the identified objectives in turn.

To address Objective 1 we have completed a systematic review of the literature to gain an understanding of previously completed work that has evaluated models of specialized oncology case management interventions. To address Objective 2 we completed an in-depth case study of the *Interlink* Cancer Care Nurses, adult program in the Greater Toronto Area. This included the development of a logic model outlining the program components and processes of care. Descriptions of who the program serves and the nature of the services provided are also presented. To address Objective 3, a template of characteristics was created and examined in relation to an a priori theoretical framework. In this framework, coordination is viewed as a system performance objective that is composed of three elements:

comprehensiveness, accessibility, and compatibility. To assess the model as represented by the *Interlink* program for its potential to facilitate coordination of supportive care, we operationally defined both quantitative and qualitative measures. Data were collected within and outside the program for each measure. Multiple data sources were used in this project including administrative and service record data from program electronic databases, data abstracted from a selection of patient charts, and structured interviews both within the program and with a purposive sample of service partners that have worked with *Interlink*.

In the discussion section we reflect on the results of the three objectives to suggest next steps for improving the coordination of supportive care for cancer patients living in the community.

Guide to the Report

Because this study had multiple components, it may be helpful to readers to have a description of how the final report is constructed. This chapter has addressed the background to the study and the context within which the study was conducted. Subsequent chapters explain the study design and offer conclusions for each of the study components. The data collection instruments used in this study are contained in a companion document of appendices.

Chapter 2 (Methods) discusses the study design, data collection, and analytic processes for each of the study components. Chapter 3 (Results) contains the findings for each of the study components: Part A is the Systematic Review of the specialized case management literature; Part B is the Program Structure and Theory; and Part C discusses Performance Criteria of Coordinated Care. Chapter 4 (Discussion) provides a synthesis of the effectiveness of a specialized case management program in coordination of SCC as identified in the preceding chapter, and provides considerations and suggestions for a specialized case management model to improve the coordination of SCC in the community.

Chapter 2

Study Methods

To address the overall and specific study objectives a mixed method approach was used to systemically collect and synthesize information. Multiple qualitative and quantitative data points have been collected from a number of different sources. These sources are listed in Table 1. The specific details of methods used are described under each of the three study objectives. Data collection took place over a six-month period: September 2003 to February 2004.

Operational Definitions of Research Terms

Unambiguous and consistent definitions of supportive care, coordination, and case management are critical to the interpretation of the results of this study. For the purpose of this study we have developed the following operational definitions of these key research terms. *Supportive care* is defined as: “the provision of necessary services to meet the physical, informational, psychological, social, spiritual, and practical needs of person living with or affected by cancer” (Fitch,

1997). *Coordination* is defined as a measure of system performance that encompasses three objectives: comprehensiveness, accessibility, and compatibility.

Comprehensiveness implies that all needs are assessed and services, resources, and expertise across the continuum of care are present in the system. *Accessibility* specifies that available resources are allocated on the basis of client need, where all required services and expertise are available in a timely manner, sufficient outreach is provided, and barriers (e.g., eligibility criteria, geographic location, etc.) do not impede those in need from obtaining necessary support. *Compatibility* specifies that client information flows across organizational boundaries as well as the existence of inter-organizational relationships and collaborations.

Case management is defined as a modality of oncology nursing practice that combines a traditional bio-medical focus with recognition of the importance of addressing the cancer patient’s /family’s supportive care needs. It is

intended to facilitate: client access to needed resources, the delivery of seamless care, and the development of a comprehensive service system. The overall objective is to support the ability of people/families living with cancer, in their efforts to adjust and adapt to the human consequences of cancer at any point on the disease trajectory (adapted from Kanter, 1989). Client centred and evidence-based practice, specialized training, standardization of assessments, continuous management, ongoing evaluation of service quality, and promotion of education are specific attributes of case management practice identified in previous studies (Brazil et al., 2003; Hollander & Prince, 2002) and deemed to be fundamental to the delivery of quality supportive care.

Study Objective 1

To study the effectiveness of specialist oncology case management in the coordination of supportive care of cancer patients as described in the published literature.

relevant literature to identify studies that evaluated a specialized case management model in the coordination of SCC. A comprehensive search strategy was developed to identify all studies pertaining to the evaluation of specialized case management and associated models in oncology in medical and social science bibliographic databases for the period 1993 to July 2003. Studies were also retrieved from searching the grey literature, hand-searching reference lists of relevant articles, and based on suggestions from experts. Articles retrieved were screened based on the set criteria for inclusion. Results from the articles meeting these criteria were extracted and summarized. Further details of the systematic review are provided in Chapter 3A (Results).

Systematic Literature Review

To address the first objective we conducted a systematic review of the

Study Objective 2

To develop an in-depth understanding of the Interlink Cancer Care Nursing model and its coordination function at the operational and administrative levels.

Case Study

To address the second objective we used a case study approach to develop an in-depth profile of the *Interlink* program and a logic model detailing the processes and expected outcomes of care.

Data collection sources included: i) program documents, ii) administrative databases, iii) patient charts, iv) *Interlink* respondents, and v) service partner respondents. Survey and interview instruments were based on the questionnaires used in the *Coordinating Supportive Cancer Care in the Community* study (Brazil et al., 2003), relevant literature, and the constructs of coordination as identified from the theoretical framework. Two instrument formats were used; a mailed survey and a personal interview, designed to examine different elements of the study.

Pilot-testing of the instruments for clarity and relevance was carried out on

a sample of respondents outside the GTA who resembled the study participants. *Interlink* nurse instruments were pilot-tested with *Interlink* pediatric nurses. *Interlink* partner instruments were pilot-tested with health care professionals who worked with *Interlink* pediatric nurses.

Interlink Program Documents

A limited review of *Interlink* program documents was undertaken. The documents reviewed included: team meeting minutes, strategic planning documents, audit results, and the *Interlink* human resources policy manual. The document review focused on: determining the program's purpose and processes for the development of the program logic model; developing a description of the program principles and structure, including governance, management, roles, and responsibilities; and finally, defining the desired program results.

In addition, two other sources of program documentation were examined: documents that had been written about the program by staff or consultants; and the statements of mission, goals, and values from the program's web site.

Annual statistic reports (i.e., patient and service figures) were also reviewed to supplement program data.

Interlink Administrative Databases

Interlink Patient Database

The Patient Database is an electronic record of information collected on the Patient Information Form on intake. When the patient is assigned to a particular nurse she/he makes additional entries to this record. This database includes patient demographics, dates of admission and discharge from *Interlink*, diagnosis, stage of illness, and reason for discharge. All non-identifying information available from this database was extracted for patients admitted to *Interlink* care between April 1, 2001 and March 31, 2002 (with data collected until patients' discharge). This timeframe was selected based on consultation with the data manager that this period denoted the most current, clean, and complete dataset. This timeframe represented a total patient sample of 700 unique cases.

Interlink Service Record Database

The Service Record Database is an electronic record of time spent on specified activities that *Interlink* nurses input directly. Date of assessment, referrals to external services, and record of follow-up activities from this data source were linked to the patient sample and compiled. In addition, types and number of *Interlink* contacts made with each patient were extracted. Complete service record data were only available up to June 2002.¹

Interlink Patient Charts

Chart Abstraction

A sample of *Interlink* patient charts were abstracted from the 700 admissions to obtain information on constructs not derivable from the *Interlink* databases. The purpose of this review was to confirm completion of an assessment, as well as, to identify the date of first *Interlink* nurse contact, the date the assessment was completed, needs assessed and unmet needs

¹ After June 2002 data entry requirements were reduced by *Interlink* and only a sample of service record data were entered into the Service Record Database.

determined, follow-up made to referrals from *Interlink* to other providers, and total number of service provider organizations involved in patient care.

The abstraction focused on those cases with some degree of service complexity. Case complexity was operationally defined as patient referral by *Interlink* to two or more organizations, as determined by the Service Record Database. The charts of patients with fewer than two referrals, whose care continued beyond June 2002, were hand-searched for potential inclusion.

A chart report form (CRF) was developed and pilot-tested on *Interlink* charts (outside of the CRF sample) for compatibility and ease of use. Following form modification, data were extracted from 113 available charts that met our inclusion criteria. These represented 16% of the total patient sample.

Interlink Respondents

Interlink Nurse Survey

The purpose of the *Interlink* Nurse Survey was to assess the presence of specialty certification, education, and knowledge in cancer care, examples of collaborative system activities with other

organizations, satisfaction with information transfer, evidence of patient-centred practice, and barriers to providing patient-centred care. Surveys were completed by nurses and forwarded to research staff.

Interlink Nurse Interview

The *Interlink* Nurse Interview had two components. The first part of the interview consisted of semi-structured questions. The areas of interest explored in this section were: factors that determine length of service (LOS), information exchange with service provider partners, and *Interlink's* perceived impact on the SCC service system.

The second component of the interview was designed using a critical incident technique (CIT) (Flanagan, 1954). The intent of the CIT was to elicit a description of how the *Interlink* nurses enacted their specialized oncology nurse role and facilitated coordinated mobilization of resources by 'observing' interactions between the nurse, their patient, and other service providers through reenactment of case situations.

CIT, originally designed to develop procedures for human resource

selection, have been used extensively in service quality and management literature (Edvardsson & Roos, 2001). Unlike other qualitative methodologies that place emphasis on describing phenomenon in naturalistic settings, critical incident studies are more highly focused on practical situations (Kemppainen, 2000).

In this study, the critical incident was the unit of analysis for developing an interpretive description of the *Interlink* nurses' work with individual patients /families and their coordination activities working with other providers. To gain insight into these issues, the nurses were initially asked to: "*Please describe a patient/family situation that you have been involved with where the supportive care needs of the patient and family were multi-faceted and where a number of different care providers were needed from several agencies to meet the patient and family needs.*" Open-ended follow-up questions were asked to obtain a comprehensive and detailed account of the incident and to maintain a focus on the interaction transactions that the nurse had with patients, families, and service provider partners in a care delivery situation that was defined, by

the number of care providers involved at any given time, as complex.

Interview guides were drafted, pilot tested, and revised based on test results. The pilot testing period was used to develop inter-rater reliability between the two nurse-interviewers. The Program's Executive Director scheduled the face-to-face interviews with the *Interlink* nurse consultants. The interviews were audio taped and transcribed verbatim. An iterative cross case analysis was conducted using induction. Theme categories were derived from the textual data to saturation, and focused on commonly occurring activities. This process facilitated the emergence of a classification scheme developed by two researchers (NP & JW) who conferred to reach agreement and was then confirmed by a third researcher (DH) experienced in qualitative data analysis methods.

Logic Model Development Process

The *Interlink* program logic model was developed over the course of two months using a nominal group process (Delbecq, Van de Ven, & Gustafson, 1975) involving the Adult and Pediatric

Nurse Consultants. Two members of the research team facilitated the process in the context of a weekly professional development meeting. During this time the nurses were asked to clarify and confirm the key program components presented to them by the facilitators and confirm the goals and objectives of the program. Once consensus was reached about the program components the participants were broken into smaller work groups and assigned a specific program component. The work groups were tasked with identifying the processes of care that belonged to their assigned program component and recorded them on a flip chart that they later presented back to the larger group for discussion, clarification, and confirmation.

It was agreed that the researchers would consolidate their understanding of the groups' discussion and organize it into a logic model format. The logic model was then sent to the nurses for review, recommended changes, questions, and concerns. There were two clearly defined iterations in the electronic communication process. Due to the time constraints of the project and the recognition that logic model

development process is an ongoing evolution, the nurses were asked to work toward consensus. They were able to reach consensus after the second iteration.

Interlink Administrator Interview

A semi-structured interview was developed and administered to the *Interlink* Executive Director. The purpose of the Administrator Interview was to obtain the administrative perspective related to: patient population served, barriers to reaching the target population at both the program and system levels, strategies for promoting the program, the program uniqueness, its current role and its strategic directions within its current context, the nature of administrative coordination efforts, enablers and impediments to achieving the program's goals, the nature of service quality monitoring activities, and finally the prerequisites for successful expansion of the program into new service regions. This interview was audio taped and transcribed verbatim.

Interlink Service Partner Respondents

Service partner instruments were intended to elicit the perspective of health care providers who worked with *Interlink* using a purposive sampling technique to ensure data richness. Twenty-seven partner key informants were identified and confirmed with common patient referral sources and destinations indicated in the *Interlink* databases. The service partner respondents represented the six catchment areas and a range of health care disciplines including CCAC case managers, as well as nurses, social workers, and physicians from institutional and agency settings. Permission was formally requested from employing organizations for the service partners to be contacted and interviewed.

To facilitate responses from physicians, the Partner Survey and Interview Guide were collapsed into a single interview instrument. This modified instrument was further pilot-tested with physicians outside the GTA who were familiar with the *Interlink* pediatric program.

Interlink Partner Survey Form

The purpose of the *Interlink* Partner Survey was to determine the function and service provision of the respondent's organization, the characteristics of patients referred from *Interlink*, examples of collaborative system activities with other organizations, satisfaction with information transfer, perceptions of the relationship with *Interlink*, evidence of patient-centred practice, and barriers to providing patient-centred care.

Partner Surveys were mailed to partner respondents along with an introductory letter and a project summary, with the exception of physicians in which case this questionnaire material was covered in the interview. Partner respondents were contacted by telephone to obtain their consent to participate, answer any questions they had about the study, and to schedule an interview time.

Interlink Partner Interview

The purpose of the *Interlink* Partner Interview was to determine: the characteristics of patients referred from the partner organization to *Interlink*, the extent of information exchanged, the

barriers to accessing *Interlink*, the service partner perceptions of *Interlink's* role, the quality of interactions with *Interlink*, the extent to which *Interlink* is perceived as providing value-added services within the system of care, and the gaps addressed by *Interlink*.

Interviews were conducted over the telephone by trained interviewers. Interviews were audio taped to ensure capture of all relevant data.

Data Analysis

Quantitative Data Analysis

Data from the Patient Database, Service Record Database, and CRF were merged into a SPSS database (version 11.5). Closed ended responses from the Interlink partner instruments were entered into a SPSS database for analysis. Descriptive, uni-variant, and cross-tab analyses were run on the data from this platform.

Qualitative Data Analysis

The constant comparative method recommended by Lincoln and Guba (1985) and originally developed by Glaser and Strauss (1967) was used for

identifying themes from textual data in the nurse interviews. Two investigators (NP & JW) read each transcript separately to develop categories of themes. A third investigator (DH) experienced in qualitative research methods verified the findings of the first two investigators. Themes were compared and consensus on interpretation was achieved among the three investigators to finalize theme categories that summarized findings across cases. Evidentiary statements, that summarized theme categories and their sub-themes, were abstracted from the transcripts and entered into a MS Excel spreadsheet.

Open-ended responses in the Interlink nurse survey and partner survey and interviews were reviewed for emergent themes. Themes derived and closed ended responses from the Interlink nurse survey were entered into a MS Excel spreadsheet. Themes derived from the Interlink partner instruments were entered into the SPSS database containing the partner quantitative data and analyzed using the same procedures previously described.

Study Objective 3

To evaluate the model of community-based specialist nursing oncology case management as represented by Interlink cancer nursing for its potential as a program to facilitate the coordination of supportive care of cancer patients in the community.

relation to Objective 2. The analysis was descriptive.

To address the third objective we used a criterion evaluation approach. This involved the development of a set of quantitative and qualitative measures that operationalized the three elements of coordination (comprehensiveness, accessibility, and compatibility) in the context of a supportive care model operating within a larger system of care. Presented in Table 2 is the framework developed, that was ratified by the Project Consultation Group. Each of the measures comes from data sources previously described in relation to Objective 2, including program documents, program databases, and the data collection instruments.

Data Analysis

The analysis for the components of the framework built upon data preparation previously described in

Table 1: *Data sources used for quantitative and qualitative analyses*

Data source	Sample	Constructs measured
Systematic Literature Review	1804 citations retrieved, 16 unique studies found	Effectiveness of specialized case management in the coordination of SCC.
Nominal Group Process	6 (all) nurses	Program theory of change, program principals and structure including governance, management, roles, and responsibilities.
<i>Interlink</i> Program Documents	Team meeting minutes, strategic planning documents, audit results, mission statement, web site	Program theory of change, program principals and structure including governance, management, roles, and responsibilities.
<i>Interlink</i> Patient Database	700 cases in period of consideration	Patient demographics, length of service, diagnosis, stage of illness, reason for discharge.
<i>Interlink</i> Service Record Database	700 cases in period of consideration	Assessment completed, sources of referrals to <i>Interlink</i> , patient referrals to external services, incidence of follow-up activities, nature and frequency of <i>Interlink</i> contacts made with each patient.
<i>Interlink</i> Patient Charts	113 (all) charts abstracted	Assessment completed, time lapse between case opened and date of first <i>Interlink</i> nurse contact, time lapse between case opened and first assessment, needs assessed and unmet needs determined, follow-up made to referrals from <i>Interlink</i> , total number of service provider organizations involved in patient care.
<i>Interlink</i> Nurse Survey	6 (all) nurses surveyed	Presence of specialty certification, education, and knowledge in cancer care, examples of collaborative system activities with other organizations, satisfaction with information transfer, evidence of patient-centred practice, barriers to providing patient-centred care.
<i>Interlink</i> Nurse Interview	6 (all) nurses interviewed	Characteristics of patients cared for by <i>Interlink</i> , barriers to patients accessing <i>Interlink</i> , determinant factors to length of service, information exchange, <i>Interlink</i> 's impact on SCC system, critical incident processes of care, evidence of tension and conflicts, <i>Interlink</i> role, gaps addressed by <i>Interlink</i> .
<i>Interlink</i> Administrator Interview	1 (all) administrator interviewed	Processes of care.
<i>Interlink</i> Partner Survey Form	26 of 27 sampled partners surveyed (96%)	Function and service provision of the respondent's organization, characteristics of patients referred from <i>Interlink</i> , examples of collaborative system activities with <i>Interlink</i> , satisfaction with information transfer, perceptions of the relationship with <i>Interlink</i> , evidence of patient-centred practice, barriers to providing patient-centred care.
<i>Interlink</i> Partner Interview	23 of 27 sampled partners interviewed (85%)	Characteristics of patients referred from the organization to <i>Interlink</i> , extent of information exchanged, barriers to accessing <i>Interlink</i> , <i>Interlink</i> role, added value of <i>Interlink</i> , evidence of tension and conflicts, gaps addressed by <i>Interlink</i> .

Table 2: *Framework for elements of coordination*

	Measure	Data types	Data source
comprehensiveness	All SCC needs assessed	Quantitative	CRF
	Needs documented in all SCC domains	Quantitative	CRF
	Direct care provision	Quantitative/Qualitative	<i>Interlink</i> nurse responses/CRF
	Referral to other service providers	Quantitative	Service record database
	System building activities	Qualitative	<i>Interlink</i> nurse responses /Program documents
	Perceived importance of <i>Interlink</i> role to comprehensive care	Quantitative	Service partner responses
	Reasons for referral to <i>Interlink</i>	Quantitative	Service partner responses
accessibility	Perceived barriers to accessing <i>Interlink</i>	Quantitative/Qualitative	<i>Interlink</i> nurse responses /Program documents /Service partner responses
	Time to first <i>Interlink</i> nurse contact from receipt of referral	Quantitative	CRF
	Time to first assessment from receipt of referral	Quantitative	CRF
	Follow up to referrals made by <i>Interlink</i> to other providers	Quantitative	CRF
	Service partner perceptions of <i>Interlink's</i> role in promoting access to services in the community	Quantitative/Qualitative	Service partner responses
compatibility	Documentation of <i>Interlink</i> working with other service partners	Quantitative	CRF
	Mechanisms of <i>Interlink</i> working with other service partners	Qualitative	<i>Interlink</i> nurse responses
	Service partner satisfaction with information exchange	Quantitative	Service partner responses
	Tension in collaborating with other service partners	Quantitative/Qualitative	<i>Interlink</i> nurse responses /Service partner responses
	Client centred care provided	Quantitative/Qualitative	<i>Interlink</i> nurse responses /Service partner responses
	<i>Interlink</i> role valued when working in collaboration with others	Qualitative	Service partner responses

Chapter 3

Results Part A: Systematic Literature Review

Study Objective 1: To study the effectiveness of specialist oncology case management in the coordination of supportive care of cancer patients as described in the published literature.

Background

In the mid 1970s there was a shift from provider oriented health care provision in North America to a more patient-centred focus (Canadian Breast Cancer Initiative, 2002; Miller & Luft, 1994). Along with this change came the promotion of various models of care, case management being one of the more frequently cited. Case management has come to figure prominently in the coordination of mental illness, stroke, and prenatal care health care services. Much of the support for the use of this model in SCC has come from studies of the fore mentioned conditions, as evident from the two case management oncology specific reviews (Canadian Breast Cancer Initiative, 2002; O'Connell, Kristjanson, & Orb, 2002). Although purported to examine the impact of case management on cancer care, these narrative reviews focused primarily on

literature pertaining to other chronic illnesses.

Purpose

The purpose of this systematic review was to evaluate the effectiveness of specialized case management as an approach for coordinating the SCC of patients. Specifically, this project's objectives involved:

- i) Identifying studies evaluating a specialized case management model in the coordination of SCC,
- ii) Assessing the quality of these studies,
- iii) Determining patient, program, and system outcomes, and where possible, comparison to other standard methods of care,
- iv) Summarizing the effectiveness of specialized case management interventions in a range of settings, and

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- v) Providing a context for the interpretation of the results of the current project evaluation.

Method

Defining Specialized Case Management

The literature suggests a lack of a consensus in defining case management (Ferguson & Weinberger, 1998; Lee, Mackenzie, Dudley-Brown, & Chin, 1998). For the purposes of this review, *specialized case management* was defined as a system of health care delivery where patients with a chronic illness are partnered with a health care provider with expertise in that illness, who assumes responsibility for matching complex client needs with services offered from multiple sources and ensuring that these needs are met (adapted from Mangan, Closson, & Stone, 1998; Tahan, 1999). The extent of the responsibilities assumed in the case management role includes the assessment of needs, development of individualized care plans, service provision, identification and linking of community services, coordination of service delivery, patient advocacy, monitoring of patient outcomes, and

support of other care providers. To be considered specialized oncology case management in this review, at a minimum, *the intervention had to involve a health care provider with specialized training in oncology, whose primary function was to provide disease related information to patients, assess for unmet needs, and link patients to appropriate SCC services.*

Search Strategy

Comprehensive search strategies were developed to identify all systematic reviews and primary studies pertaining to specialized case management and associated models in cancer. Representations of case management, containing the principles of the definition, that were considered included: Interlink Nurses, Macmillan Nurses, Advanced Practice Nurse, Clinical Nurse Specialist, care coordinator, care management, clinical navigator, coordinated care, integrated care, nurse navigator, and patient navigator.

The literature search was carried out for the period 1993 to July 2003 using the following databases: Medline, CINAHL, CancerLIT, Psychlit, and

Sociological Abstracts. Studies were also retrieved from search of the grey literature, Internet, reference lists of relevant articles, and based on suggestions from experts.

Criteria for Study Inclusion

The criteria for an article to be included in the review were:

- available in English,
- evaluation of a 'specialized oncology case management' intervention (as defined),
- intervention evaluated is adequately described,
- intervention is outpatient and/or community based,
- unit being measured (i.e., patient, program, or system) and methodology are adequately described,
- patient, program, or system outcomes are reported.

Articles retrieved were screened on the set criteria for inclusion, first based on title, secondly on abstract, and finally article full text, with all articles that could not be clearly excluded passing on to the next stage. Two reviewers independently assessed the relevant

studies for inclusion at each stage (MO & DB). Discrepancies were resolved by discussion. Results from the articles meeting these criteria were extracted and summarized. Reasons for the non-inclusion of studies were noted.

Data Abstraction

A tool was developed and used to abstract data pertaining to the interventions, methodologies, and outcomes of the specialized oncology case management studies. Study data were extracted by one reviewer (DB) and checked by a second reviewer (MO).

Quality Assessment

Study quality was assessed using grading criteria derived for quantitative (adapted from Deeks, Glanville, & Sheldon, 1996; Higginson et al., 2003) research (see Figure 1). No universally accepted grading criteria were found for evaluating qualitative studies, therefore these studies in the review were appraised based on principles of the qualitative research paradigm (see Figure 2).

Figure 1: *Grading quantitative studies*

Grade	Level
Grade I Randomized Control Trial	A Calculation of sample size Adequate description of characteristics of population of study Accrual and dropout information on participants Control for confounding variables/selection bias Outcome variables adequately defined and presented Magnitude of treatment effect indicated
Grade II Prospective study with a control group	B Adequate description of characteristics of population of study Accrual and dropout on participants Control for confounding variables/selection bias Outcome variables adequately defined and presented Magnitude of treatment effect indicated (not required for Grade IV)
Grade III Retrospective study with a control group	C Only two of: Adequate description of characteristics of population of study Outcome variables adequately defined and presented Magnitude of treatment effect indicated
Grade IV Observational study with no control group	D Only one of C

Figure 2: *Grading qualitative studies*

<p>One point was added for each principle present for a possible total score of 6 points:</p> <p>Adequate description of method for thematic development</p> <p>Inductive theme analysis used</p> <p>Themes developed from evidentiary statements</p> <p>Verification of themes by more than one researcher</p> <p>Verification of themes back with participants</p> <p>Phenomenology clearly stated</p>

Results

The literature search yielded 1804 citations. Of these, 21 articles were included in the review. Some of these studies were supplemental reports from the same primary study, for a total of 16 unique studies. Tables 1 through 4 in Appendix A summarize these studies and their findings.

Most of the studies were based in the United Kingdom (9). Five studies were based in the United States, one in Canada, and one in the Netherlands. Six studies were randomized controlled trials (RCTs), two were case control or cohort studies, five were descriptive, quantitative non-comparison designs, and three used an in depth qualitative approach.

Macmillan Nurse Program

The large portion of included studies that focused upon the Macmillan Nurse Program warrants further explanation of this model. Macmillan nursing was established in South West England in 1975 and from there these positions have spread out across the United Kingdom (Webber, 1993). Both *Interlink* and Macmillan, upon which the former is

based, are modeled on a specialized oncology nursing role (Howell, Fitch, & Caldwell, 2002). The Macmillan role encompasses the provision of assessment, information, and emotional support to patients and their families and the provision of advice, guidance and education to members of the primary health team, in addition to a research function.

Interventions Evaluated

All case managers in the interventions evaluated were Advanced Practice Nurses. Only the *Interlink* and Macmillan interventions included service partner support, such as education, as a component of the nurse's role. Of the 16 unique studies found:

- seven were based on the Macmillan model,
- one was based on the *Interlink* model,
- one intervention was similar to *Interlink* except that service partner support was provided through a separate telephone service,
- one featured community based nurses who provided patient

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- information, emotional support, and service coordination,
 - two involved clinic based nurses who provided patient information, support, and service coordination,
 - one entailed clinic based nurses who provided patient information, pain and symptom management, and service coordination,
 - one featured community based nurses who provided patient information, pain and symptom management, and service coordination,
 - two studies evaluated interventions based on a brokerage model where a nurse provided patient information and coordinated services, but did not provide counselling or any other direct care.

Outcomes Measured

Outcomes measured in the studies were classified as patient or program /system. Patient level outcomes refer to those directly relating to the patient, such as psychological status, physical function, timeliness of service, satisfaction, unmet needs, experiences of care, and survival. Program level

outcomes are measures of an administrative nature pertaining to the case management program, including roles assumed by nurses, their job satisfaction, caseload information, and cost of care provision. System level outcomes reflect the impact of the intervention on the overall system of care, including cost of health care, service partner satisfaction, and coordination of services. Of the 16 studies, 8 studies reported on patient outcomes only, 2 on program/system outcomes only, and 6 on both.

Study Quality

Two of the qualitative studies were of high quality demonstrating most of the criteria being considered, and one study contained only two of the criteria (see Table 4, Appendix A). All of the descriptive, quantitative non-comparison studies either failed to mention participant characteristics or accrual and dropout, resulting in a reduced grade (see Table 3, Appendix A). Many of these studies also contained limited explanation of outcome variables. The two quasi-experimental studies controlled for confounders and adequately defined and presented

outcome variables, but failed to report participant attrition rates (see Table 2, Appendix A). None of the RCT studies (or other studies) calculated sample size (i.e., power) (see Table 1, Appendix A). Rather, sampling in the RCTs tended to be purposive in selecting all available cases. Generally, attempts were made in the RCTs to control for confounds and outcome variables were clearly presented. A few of these studies neglected to provide participant accrual and dropout information and one did not indicate the magnitude of effect observed.

Outcomes

Randomized Controlled Trials

Of the six RCTs, four were based in the United States and two in the United Kingdom. Three studies focused on patients newly diagnosed with breast (Goodwin, Satish, Anderson, Nattinger, & Freeman, 2003; Ritz, et al., 2000) or other types of cancer (Rawl et al., 2002). In two studies (Addington-Hall, et al., 1992/Raftery, Addington-Hall, MacDonald, Anderson, & Bland, 1996; Mor, Wool, Guadagnoli, & Allen, 1995), at least 61% of patients were Stage III

or IV or receiving palliative care. Participants in these two studies had various cancer diagnoses. Moore and colleagues (2002) studied case management in patients with lung cancer across the disease continuum who had completed their initial treatment.

Newly Diagnosed

Goodwin and colleagues (2003) studied the effects of nurse case management, in addition to standard care versus standard care alone for the treatment of 335 older women with breast cancer. The primary outcome was the type and use of cancer specific therapies received in the first six months after diagnosis. In this case management model, the nurse provided care for 12 months post diagnosis. The role included education, counseling, advocacy, and service coordination depending on the needs of the patient. The authors reported that significantly more women in the intervention group received breast-conserving surgery (BCS) compared to the control group that received standard treatment. Of those women who received BCS, significantly more women in the

interventions group received adjuvant radiation and axillary dissection. Two months following surgery, a higher percentage of women in the intervention group had normal arm function compared to the standard care group.

Ritz and colleagues (2000) compared care provided by an Advanced Practice Nurse in addition to standard care to standard care alone for the treatment of 210 women with breast cancer. The roles of the advanced practice nurse included assessment and diagnosis, planning and coordination, as well as, education and research. The interventions lasted approximately one year (longer for some patients). Outcomes included quality of life and costs. Women in the intervention group had significantly less uncertainty at one, three, and six months (but not at 12 months). There were no significant differences in well-being or mood scores. There were no overall differences in overall charges or reimbursements between the groups.

Rawl and colleagues (2002) compared a computer-based nursing intervention plus standard care to standard care alone for 109 patients diagnosed with breast, lung, or colon

cancer who were receiving chemotherapy. The intervention lasted 18 weeks and consisted of assessment, counseling, education, and coordination. The primary outcomes were psychosocial functioning, anxiety, and depression. While there were no overall differences between the groups at 18 weeks, there were some significant differences at nine weeks. Patients who received the intervention had significantly less depression compared to patients in the control group, although anxiety and psychosocial functioning scores were similar between groups. In this study, more intervention patients were lost to attrition than control group patients. Patients who dropped out had significantly worse depression and social functioning scores.

Palliative Care

Addington-Hall and colleagues (1992) compared coordination of care plus standard care to standard care alone for 554 patients who were not expected to survive longer than one year. In this study, the coordinators were nurses who acted as 'brokers' of services but did not provide care themselves. Outcome measures were

the presence and severity of physical symptoms, psychiatric morbidity, use of and satisfaction with services, and carers' problems. There were few significant differences between the groups. The authors suggested that there was little effect of coordination because the coordinators did not have access to a budget for services in a setting of fiscal restraint. In addition, there were palliative care services in the setting, available to all patients. In a cost analysis, Rafferty et al. (1996) found that the group who received the coordinated services had significantly fewer in-patient days and nurse home visits.

Mor and colleagues (1995) studied the impact of short-term case management on 257 cancer patients' unmet needs and quality of life, symptom control, and mood state. In this study, the case management intervention lasted about 10 weeks, had an educational focus, and consisted of an initial home visit needs assessment, intervention plan, follow-up and a termination visit. Eligible patients had to be receiving a new course of chemotherapy and 62% were receiving palliative treatment. No significant

differences were found between the groups. The authors suggested that the finding of no difference might be explained by the design of the intervention. The intervention was primarily educational and the case manager was not directly involved in the patient's care. They also questioned the patients' capacity to act upon suggestions made by a case manager.

Moore and colleagues (2002) studied the effect of nurse specialist follow-up to treatment where information and support were provided to the patient and communication with other service partners was coordinated, compared to conventional medical follow-up. This study was limited to lung cancer patients. Sixty percent of patients were either cancer stages III or IV. Scores on select items of the European Organisation for Research and Treatment of Cancer Quality of Life Scale (EORTC QOL-14) and a patient satisfaction instrument were the independent variables. No difference between intervention and control group scores on EORTC items were found, except on one item at three months (dyspnoea lower in intervention group). Patient satisfaction was found to be high

overall in both standard and intervention follow-up, yet significantly higher on all items in the intervention group at 3 months and on most items at 6 and 12 months. On the basis of this study, Moore et al. estimated that about half of lung cancer patients would benefit from this type of intervention following treatment.

Non-experimental Quantitative Studies

Of the seven non-experimental studies, two of these studies focused on patients in the end stages of cancer, four studies contained a mixed population, and one study did not mention disease stage. The participants in four of the studies had a variety of cancer types; the remaining three studies did not report diagnosis. Only two of these studies included a comparison group (Addington-Hall & Altmann, 2000; Smeenk, de Witte, Nooyen, & Crebolder, 2000)

Many of the non-experimental quantitative studies found that patients were satisfied with the case management intervention, and most highly valued being provided information and emotional support. A few studies suggested that patients look to these

nurses to help maintain daily activities of living.

While only the Macmillan studies discussed the functioning of the case management position, these studies found that these nurses were faced with role ambiguity and conflicting expectations between their direct and indirect care provision. The single study (Smeenk et al., 2000) that examined coordination and continuity of care found that agreement on care tasks between health care providers was low regardless of intervention, but that the use of a nurse case manager slightly reduced the use of other health care providers by the patient.

Qualitative Studies

Howell, Fitch, & Caldwell (2002) studied patients with various types of end stage or recurrent cancer. Similarly, Raynes, Leach, Rawlings, & Bryson (2000) studied patients with various types of end stage cancer. The third qualitative study (Cox, Bergen, & Norman, 1993) did not mention participant stage of illness or cancer type.

Similar to the other non-experimental studies, the qualitative

studies found that patients were satisfied with the case management service, valuing the emotional support provided.

Summary

Across all studies included in this review, there was a range of specialized case management interventions, outcomes, patient populations, and health care settings. We found six rigorous evaluations where participants were randomly allocated to an intervention or control group.

The studies that focused on patients with newly diagnosed cancer (3 studies) demonstrated that patients who received a specialized case management intervention had better care (1 study - Goodwin et al., 2003) and some improved short-term outcomes up to six months post intervention, compared to the control group. In these studies, the nurse provided direct care as well as a coordination function.

In the studies where a large percentage of patients whose disease was Stage III or IV or were receiving palliative care, the benefits of specialized case management were less clear. Two studies (Addington-Hall et al.,

1992; Mor et al., 1995) did not show a benefit of case management while the third study (Moore et al, 2002) reported increased patient satisfaction (all items) in the case management group at three months.

When all studies are considered, the effects of case management on patient and system outcomes are mixed. Some of the inconsistency of findings might be attributable to the differences in the type of case management model e.g., broker vs. provider, the length of the intervention, or the disease status of the patient (newly diagnosed or receiving palliative care).

Patient Outcomes

Generally, patients were highly satisfied with and valued the case management intervention, although they also tended to be satisfied in the standard care groups. The effects of the interventions on patients' psychological state were mixed with some studies demonstrating a significant improvement in outcomes such as uncertainty or depression while others showed no difference in outcomes such as the Profile of Mood States. In studies

showing a significant difference between groups, the improvement was seen up to six months post intervention. These differences tended to disappear at 12 months. The interventions had no effect on patient survival time compared to standard care.

Program and System Outcomes

Overall, the provision of case management services did not seem to lead to increased health care costs in those studies that measured this outcome. Most physicians surveyed tended to be satisfied with this type of intervention, but they were also satisfied with standard care. Only one study (Smeenk et al., 2000) attempted to measure 'coordination of care', which the authors defined as agreement on care tasks among professional caregivers. Agreement in the system evaluated was found to be poor overall limiting the researchers' ability to detect differences between the case management intervention and standard care group.

Study Limitations In Determining Effectiveness

Richardson (2002) stated that, "There is currently little evidence that explores the best ways to organize the different elements of a cancer nursing workforce to ensure the most positive patient outcomes." (p. 414). The findings of this review support this statement as evidenced by the limited number of studies and the variable quality of this research.

Over half of the studies were without a control group of comparison, permitting comment only on effects seen relative to the intervention. From these studies it is not possible to determine the benefit of case management compared to other types of care.

In the six studies that randomized participants to intervention and standard care groups, primary study authors expressed concern regarding contamination bias. Studies that identified this as a weakness either speculated that patients in the standard care group may have sought access to components of the intervention (e.g., information and emotional support) through other means (Rawl et al., 2002; Ritz et al., 2000) or that the intervention

varied little from the standard care received by the control group (Addington-Hall et al., 1992), masking between group effects.

Furthermore, although patients in the RCTs tended to be randomized in physician clusters to avoid physicians applying knowledge of case management principles to their standard intervention patients, improvements made to the service system through the intervention of case managers (i.e., system level effects of intervention) might have positively affected the quality of standard care received (Ritz et al., 2000).

Patient selection may have also biased results. Whether they had unmet needs or not, understandably some patients in the studies reviewed did not want the addition of a nurse case manager in their care. Low study accrual and missing data due to patient drop-out in many of the studies (particularly those with participants in the end stages of cancer) may have affected the power of these analyses to detect differences.

The large number of outcomes measured and multi-itemed scales used in some studies might have resulted in

differences between groups occurring by chance (Addington-Hall et al., 1992; Moore et al., 2002). Although the comparison group studies attempted to control for baseline similarity, in at least one study (Rawl et al., 2002) it was hypothesized that it might be the patients with a higher level of resourcefulness who consented to participate in the intervention, augmenting the beneficial effect seen in that group.

Validated scales were used as outcome measures in almost half of the studies. Many of the studies also assessed patient satisfaction, which as a measure has its shortcomings in that patients may be satisfied with inadequate health care (Woolley, Kane, Hughes, & Wright, 1978).

Given the heterogeneity in methodologies and outcomes measures among identified studies, and minimal detail on how interventions were operationalized, i.e., the extent to which patient needs were identified and required services were coordinated, it is not possible to compare across interventions and disentangle the effect of any one component.

Some of the studies suggest that case management might be more effective for certain populations, e.g., newly diagnosed with cancer, in reducing the burden of the disease. Further inquiry is required to determine subpopulations for which case management might be most efficiently applied, e.g., based on need, personality characteristics, social support, and specific diagnosis, to guide appropriate targeting of the intervention.

Chapter 3

Results Part B: Program Structure and Theory

Study Objective 2: To develop an in-depth understanding of the Interlink Cancer Care Nursing model and its coordination function at the operational and administrative levels.

Background

A common limitation of the studies examined in the systematic review was their lack of a detailed description of the nature of the specialized case management intervention that was being studied, making interpretation of outcomes problematic. In this study, a process framework was applied to the examination of the *Interlink* program. The aim was to develop a clear description of the program within its environmental context and its activities related to the enactment of specialized oncology case management attributes.

In this section the findings presented are drawn from a number of data/information sources and are organized into the following way:

- Environmental Context - provides a brief description of the service environment within which *Interlink* operates and

offers a basis for making judgments about the generalizability of the report's findings.

- Program Description - divided into four areas:
 - a) Program Document Review provides a brief history of the program's genesis, governance and accountability structures, roles and responsibilities, and highlights of the Board of Directors 2002-2007 Five Year Strategic Plan.
 - b) Patient Characteristics are presented based on data from two administrative databases and qualitative data collected from the Interlink nurse interview.

-
- c) Service Characteristics are described, drawing from the same data sources as those used to determine the patient characteristics.
- d) *Interlink* Logic Model and Program Theory, was developed in consultation with all *Interlink* nurses through a nominal group process. It depicts *Interlink*'s service delivery goals in providing supportive cancer care in the community, the resources required, and the activities that are believed to be necessary to achieve the program's goals.
- Case Management - data from the program is described within a framework of attributes derived from previous work on the coordination of SCC in the community (Brazil et al., 2003). These were deemed to be contributors to the effective delivery of SCC. Results of the Nursing Information Form provided insights into how the

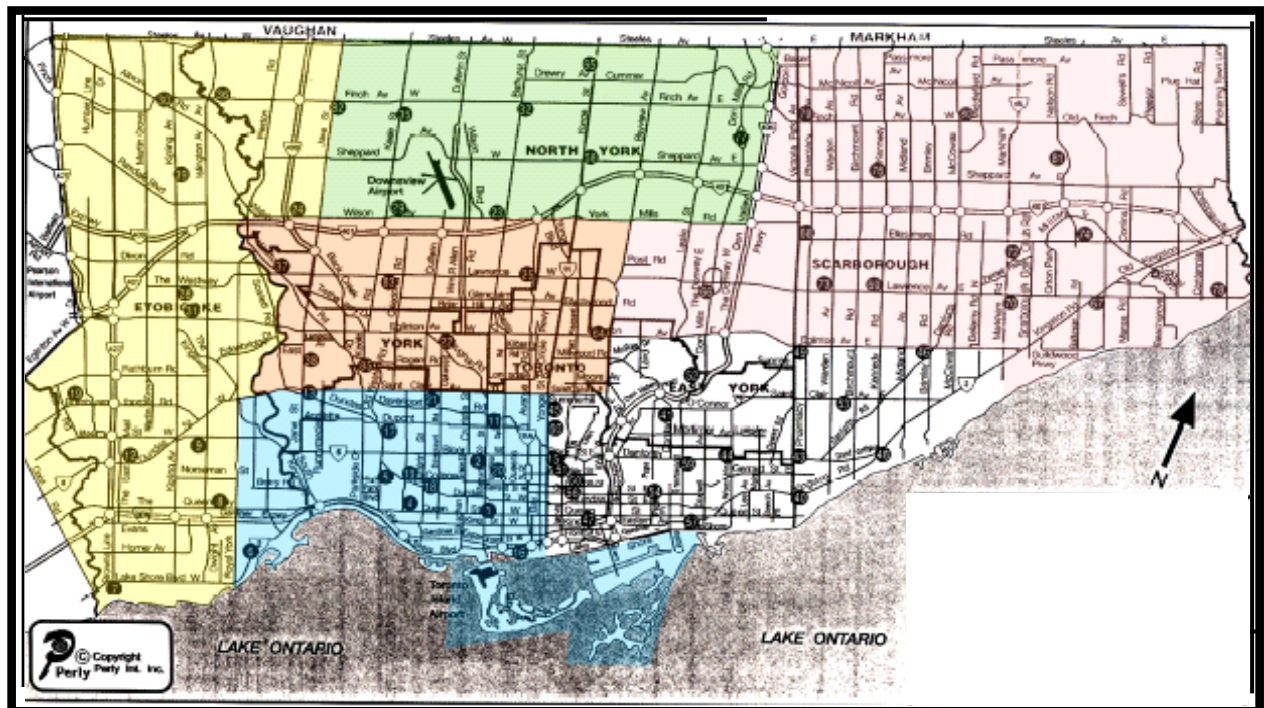
program has been implemented in relation to the specific attributes of: specialized training, client centred care, evidence-based practice, and quality evaluation.

The final part of this section summarizes the description of *Interlink* in terms of: the patient profile, the service profile, and the characteristics of case management that the program demonstrated.

Interlink has two organizational units, the Pediatric Nursing Program and the Adult Nursing Program. The process evaluation framework described above was applied exclusively to the Adult Nursing Program.

Environmental Context

Figure 1: *Interlink* catchment area and service delivery regions



At the time of the study, the *Interlink* Adult program service area corresponded to the boundaries of Metropolitan Toronto and included the boroughs of Etobicoke, North York, York, East York, Scarborough, and Toronto core (see Figure 1). As the largest city in Canada with approximately 2.5 million citizens, Toronto is among the most diverse populations in the world with

broad cultural, linguistic and ethnic variations.

The health service system has 24 hospital organizations on 35 sites and includes two regional cancer programs that are integrated into existing hospital organizations. Multiple oncology treatment services are delivered in 12 of these sites² and in

² E-mail communication, *Interlink* Community Cancer Nurses.09Mar2004

private office settings (Zanke & Evans, 2003) across the GTA. In addition, there are 5 Community Care Access Centres (CCACs) and 118 community-based MOHLTC funded agencies and a range of social programs providing support service in Toronto.

Table 1: *Socio-economic profile - Metro Toronto*³

	Metro Toronto	Ontario
Poverty Rate	22.6%	14.4%
Low Income	26%	18%
Female lone parent families	24%	18%
Home language not English or French	29%	12%
Immigrant	48%	26%

Increasing demand for services and diminishing resources are resulting in intensified systemic stresses. Service providers are questioning the longer-term

³ *Developing a New Framework for Health Services in Toronto*, Toronto District Health Council, August 2003.

sustainability of the community service sector overall (Teplitzky, Williams, & Lum, 2003).

It has been repeatedly demonstrated that supportive cancer care services in the community depend on a variety of programs that serve clients with diverse chronic illnesses and rarely are in a position to offer specialized services (Brazil et al., 2003; Fitch, 2003).

CCACs play a central role in the provision of these services (Brazil et al.) by using a resource allocation or brokerage case management model.

A recent Toronto District Health Council document (Teplitzky et al., 2003) reported that a number of changes in the way CCACs operate have had a perceived impact across the broad base of community support programs in the GTA, intensifying the pressure on this sector.

In addition to brokering services, the CCAC role has been perceived as providing service coordination or case management for clients in need of care and support in the community. However, a general reduction in resources available to broker, a

narrowing array of contracted services, and an increased demand for a broader range of services to meet the needs of individuals with chronic illnesses, disabilities, and needs related to aging, creates an environment in which there is greater likelihood that individuals and families will have difficulty accessing the services they need, when they need them (Teplitsky, et al.). *Interlink* is one of a few specialty cancer programs in this environment.

Program Description

Document Review

Interlink's program documents were reviewed. They included: Team Meeting minutes, Strategic Planning documents, Audit Results, and the Human Resources Policy Manual. These documents were reviewed to develop a greater understanding of the program's internal operating structures and processes. Informal dialogue occurred between researchers and

Interlink personal related to the program documents to ensure that our understanding and interpretation of the documents was consistent with their intent and application.

History

In 1987 Joan Foy and Gaye Evans, two experienced oncology nurses, established *Interlink Community Cancer Nurses*, as a solution to the combined problems posed by disease and related service delivery systems with the aim of ameliorating the human consequences of both.

The service was initially limited to providing adult supportive care in the Toronto area. However, in 1999 the need for pediatric supportive cancer care services became evident. As a response, *Interlink*, formed a funding partnership with the Candlelighters Foundation to pilot a pediatric community oncology nurse program at the Hospital for Sick Children in Toronto. Over the course of three years this project was expanded to five sites across the province. In 2002 the Ontario Ministry of Health and

Long Term Care, addressing the program's concerns about sustainability, agreed to provide ongoing funding to the existing services and located an additional Interlink pediatric nurse at the London Regional Cancer Centre.

In contrast, the *Interlink* adult program currently continues to be supported through fund-raising efforts and remains geographically limited to the Greater Toronto Area (GTA).

Governance and Accountability

Interlink is a community-based, not-for-profit organization (see Figure 2). As such it has a volunteer Board of Directors consisting of 12 members. The Board, responsible for the overall governance and financial stability of *Interlink*, meets bi-monthly. Presently its membership consists of a cross section of business, public sector, and community representatives.

Mission

Interlink's mission is stated as: "Interlink Community Cancer Nurses is a not-for-profit community nursing program providing, children, adults and families experiencing cancer, access to care and support. Our nurses act as a specialized resource to health care professionals in meeting patient and family needs."

Vision

The program's vision is: "To act upon recommendations from people living with cancer regarding their care and quality of life; advocate for them at the provincial level. To inform and educate other health professionals who request knowledge on oncological nursing care in order to improve the quality of life for people living with cancer."

Values

The values upon which the program and the individual nursing practices are established have been expressed as: respect for individual diversity based on culture, ethnicity, religion, gender, sexual orientation,

and age; respect for individual's right to be cared for in the comfort of their home or the setting of their choice; respect for each person's dignity and independence, and a commitment to working from a position of cooperation and collaboration with all available health and social programs and services.

Goals

The program's intervention goals are to minimize the trauma experienced by a person diagnosed with cancer, promote optimal functioning and wellbeing, and improve or maintain quality of life (Howell & Jackson, 1998). The intended mechanism for achieving these goals is the provision of services in the patient's home and across the disease trajectory. The principles of client centred care are intended to be central to the planning and provision of interventions.

In the 2001/2002 fiscal year, *Interlink's* total budget was \$809,738. Approximately 40% of these funds were received through a

contractually limited transfer payment relationship with Cancer Care Ontario (CCO). At the time of the study the accountability requirement for these funds was the submission of an annual financial report. In total, 72% of the program's budget went to the provision of patient services.⁴

5-Year Strategic Plan

In the fall of 2002 the Board of Directors for *Interlink* ratified a 5-year strategic plan. The goals for that period are: to increase the number of adult nurses to one in each regional cancer centre including Hamilton, Ottawa, London, Kingston, Sudbury, Thunder Bay, Windsor, and Oshawa. It is believed that a partnership between regional cancer centres and *Interlink* will allow nurses early access to newly diagnosed patients increasing the quality of life for those experiencing cancer.

The need for two people working in the area of fund development, an increase in clinical practice development from part-time to full-

⁴ Personal Communication, *Interlink* Executive Director, 04 March 04.

time, and a full-time researcher were also identified as key to the strategic development of the program. Finally, the partnership with CCO was acknowledged as an important relationship in the program's ability to provide community supportive care services into the future as part of the cancer care system.

Roles and Responsibilities

At the time of this investigation the total staff complement of *Interlink* was the equivalent of 16.5 full time positions (FTE). The roles within this complement included: Executive Director (1 FTE); Director of Development (1 FTE); Practice Development Officer (0.5 FTE); Pediatric Nurse (6 FTEs); Nurse Consultant (6 FTEs) Executive Assistant (1FTE), and Office Manager (1FTE). Those roles that are engaged in direct service or program sustainability will be briefly described below.

Management - Executive Director

This role is responsible for all strategic, political, clinical practice, fundraising, marketing, finance, personnel and administrative outcomes of the program.

The Executive Director is responsible to the Board of Directors and reports to the Chair. This relationship represents an ongoing commitment to the patients and families living with cancer who received service from the *Interlink* program.

Sustainability - Director of Development

This position is responsible for the effective development of resources to support the short and long-term financial needs of *Interlink* Community Cancer Nurses through the planning, implementation, and coordination of all fundraising activities. This role, while working closely with members of the Board of Directors and other volunteers, reports to the Executive Director.

Standards - Practice Development

Director

This role is responsible for advancing the clinical practice of Interlink nurses to ensure the delivery of quality patient care. The Practice Development Director does this by planning and implementing activities that advance the *Interlink* nurses knowledge, practice, and research. These activities include: the reflective practice program; development of educational modules, i.e., Comprehensive Nursing Guide to Ovarian Cancer (Howell, 1998) and promoting an understanding and application of research. At the time of this study this position was operating as a half-time position due to resource limitations.

This role is responsible for providing the Board of Directors with bi-annual reports on the Practice Development Program. Accountability is to the Executive Director.

Service Delivery - Pediatric Nurse

This position is responsible for extending the care of the child with cancer and family from hospital into home, assisting the child and family in their efforts to adjust to the disease and its treatments, and to contribute to the provision of comprehensive /coordinated care by collaborating with the hospital or satellite-based oncology team.

Interlink pediatric nurses are positioned in five regional cancer centers across the province, including: Hamilton, Sudbury, Ottawa, London, and Kingston, as well as Toronto's Hospital for Sick Children. The Pediatric nurse role has a dual reporting responsibility. Each nurse reports to the Executive Director of Interlink and the Director of Oncology in the partner health science centre.

Service Delivery - Nurse Consultant

(Adult Program)

The practice of each nurse is limited to a specified geographic location within the GTA. The *Interlink* nurse job description states: the nurse is responsible for providing advanced

level nursing care, which includes assessment and counseling, education, consultation, research, and community development to enhance the quality of patient care, to advance evidence-based practice in cancer nursing, and to influence health policy and program development. In terms of professional education and preparation, the *Interlink* nurse is expected to:

- Possess a current Registered Nurse, Certificate of Competence
- Hold a current CON(C) certificate from the Canadian Nurses Association and/or the Oncology Nursing Society
- Minimum of five (5) years recent oncology nursing experience
- Baccalaureate or Masters preferred
- Demonstrated competence in clinical nursing practice related to the care of the adult oncology /palliative care
- Recent experience as a nurse in a care-centre other than hospital, such as home care, visiting nurse, ambulatory care

- Demonstrated ability to work with other health care professionals in care delivery
- Demonstrated ability to teach, consult and negotiate.

The *Interlink* Nurse Consultant role is operationalized within an independent practice framework and reports to the Executive Director. The scope of clinical practice revolves around the application of enhanced specialty knowledge and skill to manage symptoms and side effects of treatment, counsel patients in coping-strategies, teach self-care behaviours, and monitor the response to treatment and nursing interventions. The *Interlink* nurse transfers this knowledge and skill to: patients, family members, members of the informal support system, and non-specialized service providers, as needed. The nurse is expected to use anticipatory judgment to identify early signs and symptoms and prompt early intervention and appropriate treatment. Professional performance is reviewed annually and measured in relation to: clinical practice,

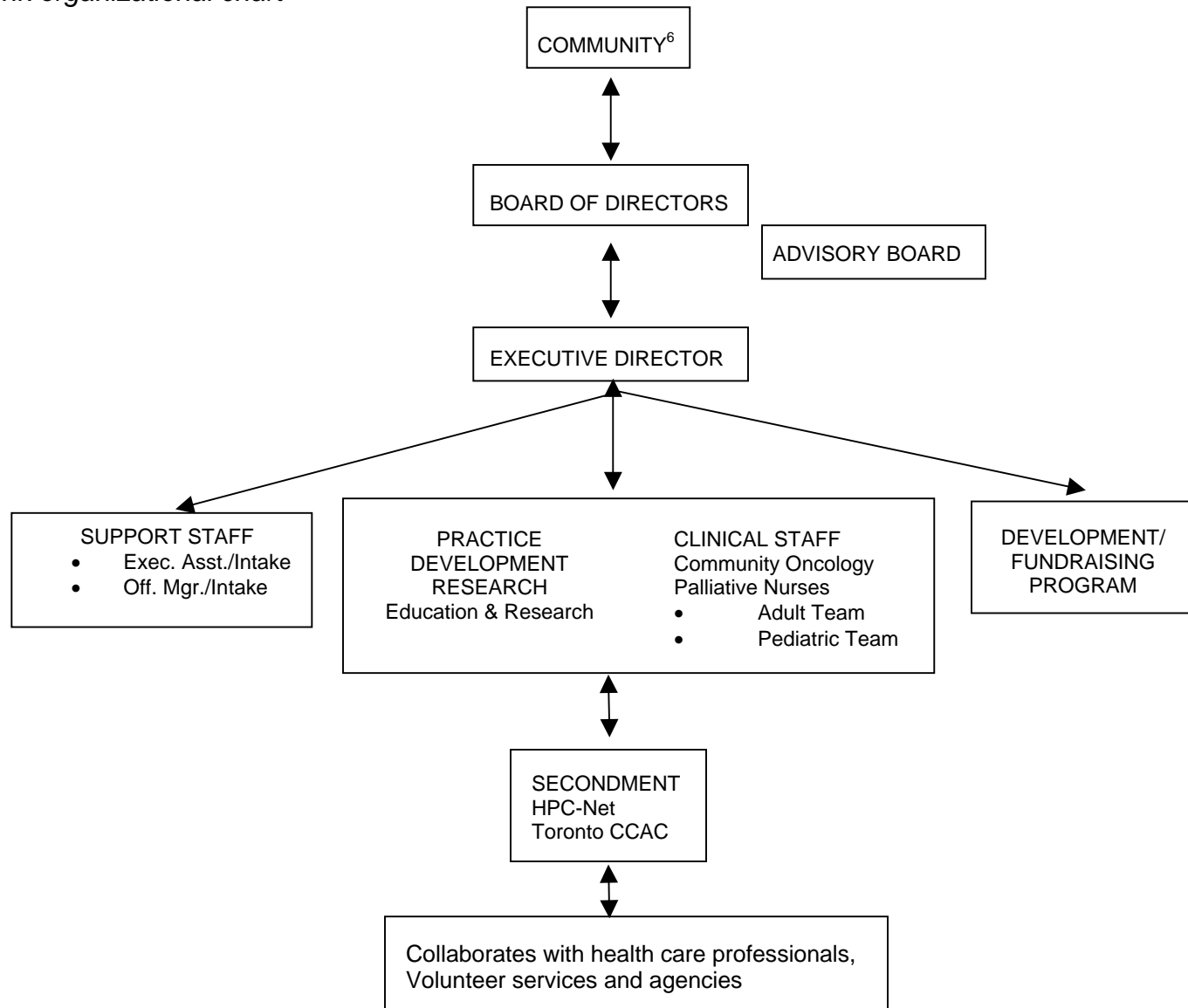
patient/family centred care,
teamwork, community development,
and professional activity. The
desired outcome is optimal patient
/family wellbeing and quality of life
living with cancer in the community.

On average the Nurse
Consultants carry a caseload of
approximately 50 patients at any
given time. The nurses each deliver
care to an estimated 150 patients
over the course of any 12-month
period.⁵

We were advised that this statement of
responsibility pre-dates the release of the
Canadian Association of Nurses in
Oncology Standards of Care (September
2002). In both intention and current
practice, this position aims to correspond to
the current 'Specialist Oncology' nursing
role defined by the CANO standards.

⁵ *Interlink* program management
records, Executive Director.

Figure 2: *Interlink organizational chart*



⁶ Interlink Community Cancer Nurses, Human Resource Manual.

Patient Characteristics

In the 2001/2002 fiscal year, 713 patients were recorded as admitted to the Interlink program. Thirteen (13) of these patients were admitted twice during the study year. These readmissions were excluded from the analysis. The quantitative data presented in this section were derived from two program administrative databases. The qualitative data represent the nurse perspectives obtained in the Nurse Interview Guide.

Gender

Approximately two-thirds of the patients served by Interlink are women (see Table 2).

Age

Interlink's patient population tends to be older (see Table 2). Eighty-two percent (82%) of the patients during the study year were over fifty years of age.

Diagnosis

For the purposes of this report, diagnoses that were reported in the administrative database were grouped into major disease site categories (see Table 2). Approximately 60% of

patients had gastrointestinal, breast, or lung cancers.

Table 2: *Patient characteristics*

Characteristic	Patients (N=700)	
	n	%
<u>Gender</u>		
Male	271	39.3
Female	418	60.7
Missing	11	
<u>Age (yrs)</u>		
20-49	122	17.7
50-69	287	41.7
70-79	187	27.2
80+	92	13.4
Missing	12	
<u>Major Disease Site</u>		
<u>Categories</u>		
Gastrointestinal	162	23.6
Lung	127	18.5
Breast	118	17.2
Hematology	64	9.3
Ovarian	54	7.9
Prostrate	50	7.3
Head & Neck	38	5.5
Other	77	10.7
<u>Stage of Illness</u>		
Early stage	110	16.4
Advanced	300	44.6
End-stage	237	35.3
Remission	25	3.7
Missing	28	

Stage of Illness on Discharge

Available data did not permit the reliable determination of the patient's stage of illness at admission. Consequently, stage of illness was determined at the time of the patient's discharge from the program (see Table 2). In approximately one-quarter of the cases the reason for discharge was reported 'deceased'. The notion that Interlink tends to serve patients with more advanced disease was born out by the fact that the majority of other patients were reported as in advanced or end-stage cancer upon discharge.

Reason for Referral

It should be noted that in addition to service provider referrals, patients, and their families are able to refer themselves to the *Interlink* program, (see Table 2). While patients may have been identified as having multiple reasons for referral, the reason most commonly recorded was the need for 'support'. Referral sources were least likely to identify pain and symptom management as a reason for referring.

Table 2: Patient characteristics
(continued)

Characteristic	Patients (N=700)	%
<u>Reason for Referral</u> [□]	n	%
Support	520	72.7
Assessment	292	40.8
Linking	282	39.4
Monitoring	252	35.2
Education	229	32
Pain management	77	10.8
<u>Identified Problem(s)</u> [□]		
Lack of support	492	63.7
Lack of service	315	40.8
Disease information	249	32.3
Treatment decisions	218	28.3
Pain & Symptom management	188	24.4
GP Visit*	134	17.4
<u>Geographic Location</u>		
Etobicoke	149	21.3
City Core	138	19.7
East York	126	18.0
Old York	123	17.6
North York	91	13.0
Scarborough	73	10.4

□ Multiple issues were identified for single patients resulting in percentages totaling more than 100%

* Refers to difficulty in arranging a visit with a physician or the lack of a family physician.

Identified Problem(s)

The major problems identified on admission were consistent with the reasons for referral (see Table 2). The perceived need for support was most frequently identified while pain and symptom management was reported least frequently as an identified patient problem.

Geographic Distribution

Interlink's adult program catchment area is divided into six service regions (see Figure 2). Referrals to the program were reported by service region. Four of the six service regions received comparable levels of referral. North York and Scarborough received the least number of referrals. During the period of study, the latter service region was a developing area of practice. The former service region was reportedly in need of an increase in its community promotion activities during the study period.

Nurse Consultants - Patient Description

Qualitative data from the Nurse Interviews provided richness to the patient profile that could not be detected from the quantitative data alone.

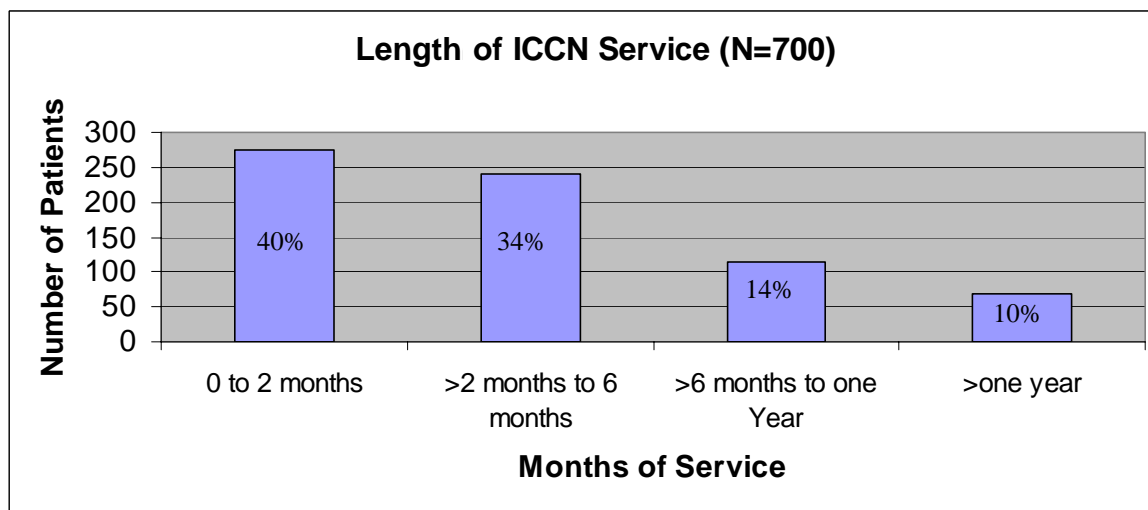
Qualitatively patients were characterized as diverse with differing

care needs according to: cancer trajectory stage; financial resources; access to internal and external support systems; level of self-sufficiency; disease presentation; culture, and living circumstances. Patients accessing the service were described as low to moderate income, tending to be socially or culturally isolated with few supports. They were described as those with complex family dynamics, adjustment problems, complex disease presentation, and complex treatment side effects.

Service Characteristics

The data reported in this section will focus on those activities that require the use of specialized oncology nursing knowledge and demonstrate the mobilization of resources. 'Specialized Oncology Nursing & Supportive Care' and 'Coordinated Mobilization & Linkage to Resources' are the program components that represent these activities, and are depicted in the logic model (see Figure 4, page 64). This service profile is based on data from the same databases as the patient profile and the qualitative data derived from the Nursing Interviews.

Figure 3: *Interlink length of service*



Length of Service (LOS)

Forty (40) percent of *Interlink* patients received service for two months or less (see Figure 3). Seventy-four (74) percent of patients were discharged within six months of intake. A small percentage (10%) received service for longer than 1 year.

Triangulated qualitative findings revealed that *Interlink* nurses characterized the short-term patient population (those in the program for less than two months) as:

- (1) patients who were newly diagnosed requiring information to aid decision-making or those having family support, and needing minimal advice and support to become self-sufficient and
- (2) patients who were palliative and either

die or were able to be linked to appropriate palliative care services. Statements from the nurse interviews portrayed the short-term patient needs as follows.

“ A group of patients that may need you to provide them with information, discuss disease and treatment options, they are quite self-sufficient, independent, need information, are good at gathering that information and you may help them sort through but they are able to access resources on their own. So you provide them with information, they become more independent and autonomous and then they don't necessarily need you”.

A longer length of service was provided for patients for various reasons, such as:

- (a) requiring multiple sources of support throughout the illness trajectory;
- (b) experiencing difficulty in adjusting/adapting to cancer with resultant anxiety and/or depression,
- (c) needing ongoing support due to advancing disease or impending death,
- (d) few social supports or services available;
- (e) pre-existing psychosocial or financial stressors, and
- (f) complex symptom issues or treatment side-effects. As noted by one nurse, two months in the trajectory of cancer is not very long since most treatment regimes are seldom less than six months in duration.

Patients described as socially isolated, such as the elderly or mentally ill and in the program for extended periods of time beyond their need for cancer-related support, were identified as the exception. In these situations *Interlink* appeared to be providing a safety net in the absence of community supports. The following statements portray some of the ongoing needs of

the cancer patient population served by the program over longer periods of time.

“Then there’s the family. If there’s a problem in the family, I worked for a long time with a young woman whose father had cancer, but I worked to help her cope with his dying. His disease was progressing and she was able to see him through to the end and that was largely because she had someone to help her through...She had someone to talk to and support her through all that so that’s a role.”

“A person that feels that their whole life is in chaos and we see that and it can be very much of a roller coaster ride but it’s those people that remain in the chaos pattern that it doesn’t tend to settle down, they remain definitely longer.”

“But sometimes some people don’t really, they can’t adjust to this diagnosis, they’re full of fear or they don’t want it, or don’t really take it on so they have a lot of difficulty adapting. As stated by one patient, ‘Well I am supposed to pick up the pieces now but I don’t know what the pieces are.’”

Assessment Made

Of the total sample of patients admitted to Interlink during the study period, 473 (67.6%) were recorded as having had a full assessment completed using the program's standardized

Table 3: *Assessment of patient need (n=700)*

	Assessed		Not Assessed		Total
	n	%	n	%	N
<2mos	126	46%	149	54%	275
2-6mos	198	82%	43	18%	241
6-12mos	97	84%	18	16%	115
>1yr.	52	75%	17	25%	69
Total	473		227		700

assessment form. For those who had an assessment recorded, the median length of time between admission to the program and the assessment was eight days. Approximately 50% were assessed within seven days. Seventy-nine percent were assessed within 14 days and 91% were assessed within 21 days. Patients who had been in the program between two and six months (198/241) had the greatest number of assessments on record (see Table 3). Those patients that were in the program

for less than two months had the lowest level of assessment recorded.

To further explore this finding we randomly sampled 30 patient charts from the 227 with no assessment recorded in the Service Database (10 early stage, 9 advanced and 11 end stage). These 30 charts had not been included in our chart abstraction. We found that in 5 of the 30 (17%) charts there was an assessment form completed that had not been recorded in the database. In the remaining charts we looked for other documentation of assessment and/or reason for full assessment not being done. In nearly all cases there was evidence of assessment or attempt to contact by the nurse. Of the 25 files with no assessment form completed, the documented reasons included: no identified need (7), declined service (6), single need with link made (4), family support only, patient had no needs (3), unable to contact (2), death (1) no cancer (1) and no reason in chart (1). Thus the database appears to underestimate the true rate of assessment.

Linkage to Other Services

Referrals to the Program

The administrative database recorded referral sources (see Table 4) and the number of linkages made by Interlink nurses to other services over the course of the patients' involvement with the program.

Table 4: *Sources of referral*

	N	%
Hospitals	248	35.4
Self-referral	184	26.3
CCACs	134	19.1
Other Health Care Practitioners	113	16.1
Other	21	3
Total	700	100%

The major referral sources for the Interlink program were hospitals across the GTA, self-referral, the CCACs and other health care practitioners. One specialty cancer centre provided slightly more than half of the hospital referrals. The referrals made from other health care practitioners included physician referrals. However, less than 10% of those referrals were recorded as being from physicians. The remainder was

from registered nurses and social workers in the community.

Referrals from the Program

Of the 700 patients that were admitted to the *Interlink* program during the study period, the Administrative data showed that two-thirds of patients had no linkages made for them by the program. Thirty-four percent (34%) were recorded as having one or more links made to other service providers. There was an association between longer patient LOS and the presence of one or more linkages. The highest proportion of linkage was reported for those patients whose LOS was greater than 12 months (see Table 5).

Table 5: *Linkages made by LOS*

LOS	No Link (N)	≥ 1 Link (N)
< 2 Mos.	213	62
2-6 Mos.	159	82
6-12 Mos.	60	55
> 12 Mos.	33	36
Total	465	235

Patient Contact

Interlink nurses recorded having just over 1,500 fact-to-face contacts with their patients. Ninety-four percent

(94%) of those contacts were made in the patients' homes. The other six percent were classified as 'Institutional Visits'. On average two home or institutional visits were made to each patient (median = 1).

The administrative data also revealed that of the patient records that showed five or fewer total patient contacts made, 71% of those patient records also showed 'No Assessment' while only 22% of this group was identified as having an 'Assessment Completed'.

In addition, 7379 telephone calls were recorded as being made to the patient/family or on behalf of the patient served. The median number of calls to/for a patient or family was seven.

Interlink Logic Model & Program Theory

The program logic model was developed in consultation with all *Interlink* nurses through a nominal group process. We were able to achieve consensus among the nurses with respect to the model's content.

Logic modeling is an ongoing and evolving process that diagrams the cognitive structure of a change process

(Alter & Murty, 1997). The logic model depicts the program's approach to care delivery and the activities that are believed to be necessary to achieve the program's goals and meet the challenges faced in delivering SCC in the community.

The *Interlink* program is designed as an independent practice approach to provide community-based specialized oncology nursing. The approach has been modeled on the Macmillan nurse program in the United Kingdom (Bunn, 1988) and adapted to the Ontario environment. The target population for the adult program is any adult cancer patient in the GTA in need of specialized oncology support for the management of cancer, its treatments and side effects.

The *Interlink* Logic Model (see Figure 4) begins with a *Problem Statement* that describes the well-documented experiences of individuals and families living with cancer in the community. Specifically, the problem is defined in terms of the combined impact of the disease and treatments and the barriers to accessing community-based systems of support.

Note: *Interlink* engages in other activities and processes that do not appear in the logic model. For example, fundraising activities address program sustainability, however, they do not contribute directly to *building a system of support around individuals and their families*. For this reason they are not included in the logic model.

A strategy for solving this problem was constructed around four *Program Components*: 1) Specialized Oncology Nursing & Supportive Care, 2) Coordinated Mobilization & Linkage to Resources, 3) Community-based Education & Research, and 4) Community Resource Development. These components are linked in a casual chain toward the *Program Goal* (Alter & Murty, 1997). They are connected such that they amplify the impact of activities and processes undertaken in each component to achieve the desired positive change for patients and families living with cancer in the community.

Inputs/Requirements, delineate the resources that are needed to implement the activities and processes of the program components. Often these are described exclusively in financial terms. In this model the knowledge skills and

attitudes that are foundational to operationalizing a model of specialized oncology nursing have been made apparent. *Activities/Process/Methods* describe the actions assumed to be necessary to achieve the desired results. *Results/Outcomes Objective: Short-Term*, describe the immediate changes that are the products of the activities identified above them. There is a logical link or direct relationship between the activities and the results.

Finally, proponents of the program believe that the activities undertaken as delineated under each of the program components will culminate in what is described as "*Results/Outcome Objectives: Long-Term*". Long-term outcomes are identified at two levels: those that are expected to have an impact at the level of the system of care; and those whose impact will be felt at the level of the patient and family.

This logic model represents the *Interlink* program theory and coupled with a theoretical framework of coordination, guided our examination of the program as a model of community-based specialized oncology nursing.

Figure 4: Interlink Community Cancer Nurses - Program Logic Model

Overall Problem Statement

Impact of cancer is multidimensional and affects all aspects of life: physical, psychological, social, functional, financial and family dynamics. People living with cancer are at high risk for suffering, financial burden, depression, anxiety, adjustment disorders and psychological morbidity. Nevertheless, individuals with cancer experience barriers to accessing the supportive care services and specialized cancer providers in the community they need to enable their adjustment to cancer and adaptation to the human consequences of cancer and to prevent risk of physical and psychosocial consequences of cancer and its treatment.

Program Components

Specialized Oncology Nursing & Supportive Care
"specialized oncology nursing role"

Coordinated Mobilization & Linkage to Resources
"linking system parts"

Community-based Education & Research
"specialized nursing resource"

Community Resource Development
"policy and program advocacy"

Overall Program Goal

To build a system of support around individuals and their families living with cancer in the community that is relevant to their needs and facilitates their efforts to adjust to the consequences of cancer and its treatment at any point on the disease continuum.

Inputs/Requirements

- In-depth knowledge of cancer patient population clinical and supportive care needs gained through a minimum of 3-5 years experience in cancer care
- Specialty certification and education in cancer care, demonstrating core competencies as identified in *Canadian Oncology Nursing Association Standards of Care for Individuals and Families*.
- A health service delivery model that supports: in-home, client centered care, independent specialized oncology nursing practice, and continuous learning.
- Knowledge and ability to advocate within systems of care at patient, program and policy levels.
- Adequate funding base to support individualized, in-home service delivery and independent nursing practice role.



Activities/Processes/Methods

*Conduct comprehensive in-home assessment of supportive care needs to clarify treatment goals and expectations with attention to psychosocial and physical risk management, crisis interventions, and symptom management needs.
**Provide direct therapeutic interventions and mobilize patient's support systems, including resources from other agencies, to address needs.*
** Provide information, educational coaching and anticipatory guidance to patient/family to facilitate patient/family knowledge and understanding of disease and treatment and coping in dealing with sequelae of cancer.*
 *Act as a clinical consultant to and collaborator with interdisciplinary providers in the management of pain, symptoms and treatment related side effects.
 *Support adaptation and promote patient/family integrity along the continuum and following death through the provision of supportive counseling, emotional and psychological support.
 *Support reintegration into work environment or other aspects of daily life and the school environment for children.

**Facilitate timely access to address supportive care needs by direct referral to formal/informal agencies and resources available anywhere in the system.*
 *Support patient/family self-sufficiency in accessing resources that address their unique needs through the provision of information about services of benefit.
**Act as a system navigator as needed, initiate referrals and monitor linkages to formal/informal services/resources to build a coordinated system of support around patient/family.*
 *Mobilize school-based supports for children with cancer to ensure access to continued schooling by educating teachers and classmates.
**Advocate for the patient/family to ensure the provision of services relevant to their unique needs by linking system parts in the development of coordinated care approaches.*
 *Facilitate a coordinated system of support for patient/family through communication and collaboration with other providers and agencies.

*Incorporate evidence-based knowledge into practice of specialized oncology nursing role.
 *Act as a preceptor to nursing students in colleges and universities to advance their knowledge and understanding of care of cancer patients/families.
 *Provide education, mentorship and role modeling to primary care providers to ensure effective delivery of care.
 *Act as a knowledge resource by disseminating specialized oncology nursing knowledge of the care needs of cancer patients/families at conferences, presentations and through publications and evidence-based monographs.
 *Partner with others to participate in and conduct research to advance nursing practice in the care of cancer patients and their families.
 *Use reflective practice and peer review to advance the quality of specialized oncology nursing care and deepen the knowledge and understanding of cancer patients/family needs.

*Act as an advocate through membership in relevant committees or action groups to develop policies, programs and resources for persons living with cancer in the community.
 *Contribute to the identification of gaps in community-based supportive care resources for patients/families.
 *Participate in the planning, development and implementation of effective supportive care programs for cancer patients and families.
**Disseminate information to community service providers to build understanding and knowledge of the issues, concerns, and needs of cancer patients/families and the role of specialized oncology nurses in addressing needs.*
 *Network with service providers to strengthen partnerships that promote collaborative care relationships across the cancer continuum.

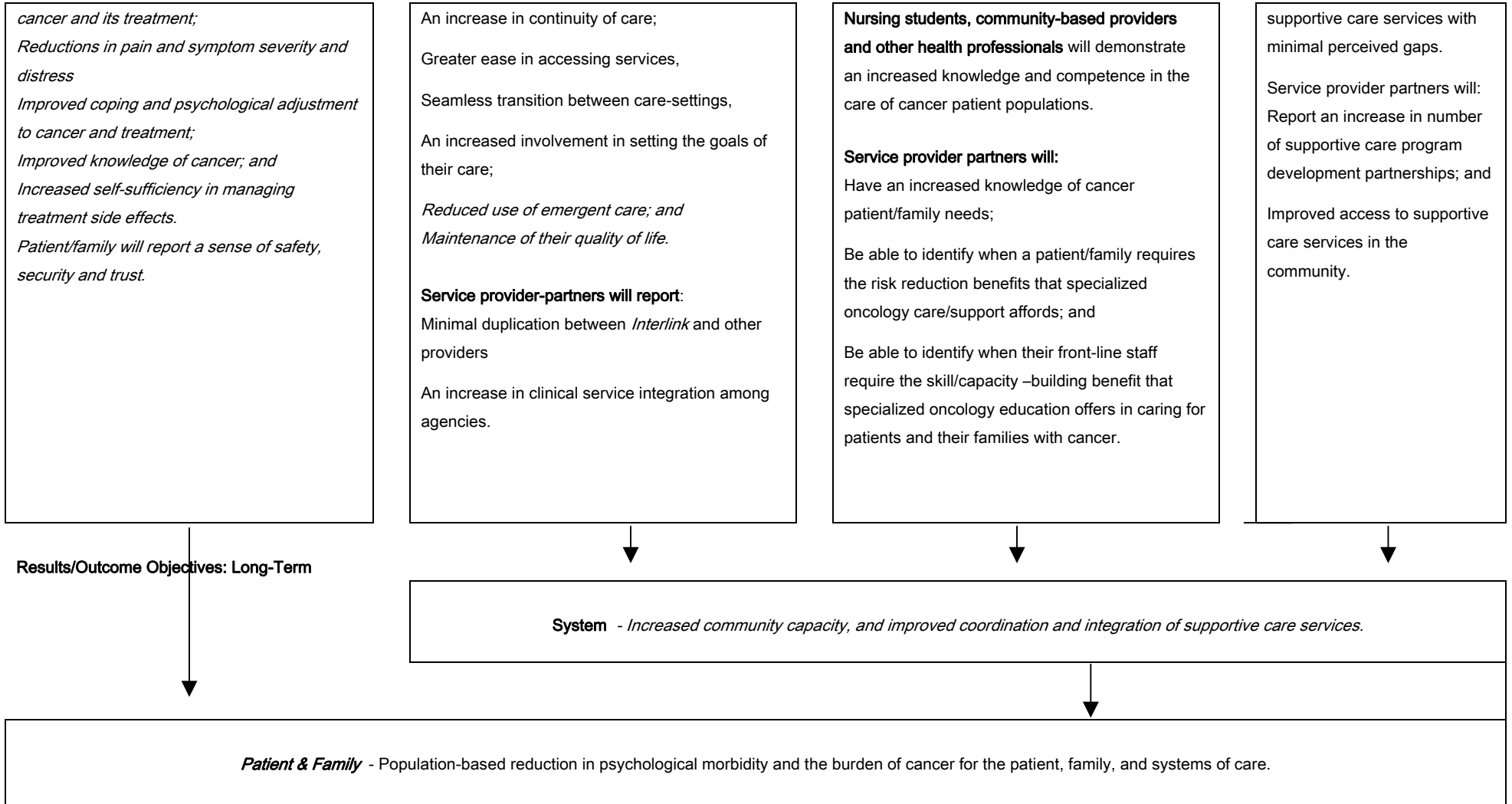
Results/Outcome Objectives: Short-Term

Patients and families will experience:
Reductions in patient complications related to

Patients and families will report:
 A reduction in unmet needs;

Patients and families will:
 Report satisfaction with quality of care.

Patients and families will:
 Report improved access to



Case Management Characteristics

Within the context of this study, *Case management* is defined as a modality of oncology nursing practice that combines a traditional bio-medical focus with recognition of the importance of addressing the cancer patient's /family's supportive care needs. It is intended to facilitate: client access to needed resources, the delivery of seamless care, and the development of a comprehensive service system. The overall objective is to support the ability of people/families living with cancer, in their efforts to adjust and adapt to the human consequences of cancer at any point on the disease trajectory (adapted from Kanter, 1989).

Each of the *Interlink* nurses completed a Nurse Information Form that sought to explore a number of criterion that were deemed to be desirable attributes of a specialized oncology case management model. These characteristics had been identified in previous studies (Brazil et al.; Hollander & Prince, 2002) as important to the delivery of supportive care in the community. These measures were of particular interest to

the researchers as they related to the program's activities and goals in conjunction with the nurses' role.

Specialist Trained

In a closed ended question, the *Interlink* nurses were asked, "What education have you received?" All of the adult program nurses had their Canadian Oncology Nursing Certification CON(C). This is also a pre-requisite of hiring. Four of the six nurses had their BScN degree. One had a nursing diploma and a BA and another had her nursing diploma only.

None of the nurses reported training in case management. Although, one nurse had worked as a care coordinator in a brokerage model of case management, prior to becoming an *Interlink* nurse. One of the six nurses reported having had some training in issues related to the delivery of health care services in a multicultural environment.

With one exception, the group of adult nurses had worked for *Interlink* from 2.5 to 12 years and had worked in a community setting for 2.5 to 28 years. Overall, the nurses had 2 to 14 years of oncology experience. All had continuing and recent education in cancer and palliative care.

Client Centred Practice

A program guiding principle, all of the nurses reported focusing their care around the principles of client centredness. Indeed when asked to identify the six most important factors that influenced their decision-making about planning/delivering service/care, the two factors that were identified by all of the nurses were,

'The patient/family's expressed needs/wishes' and 'The patient's psychological/emotional status'. When asked if there were barriers to enacting client centred care, four of the six nurses identified reduced, inadequate or absent services in the community as a limiting factor in the provision of client centred care.

Evidence Based Practice

All but one nurse reported participating in an annual reflective practice process. On a monthly basis the combined pediatric and adult nursing staff met to engage in an in-depth review of a particular patient/family situation as part of their professional development activities. The nurse operates within a formalized framework that guides the reflective

process whereby empirical knowledge is examined in relation to the case practice situation (Howell & Pelton, 2001).

Within *Interlink* the evaluation of nursing performance is based on the CANO standards. However we were unable to find any evidence that there had been development of evidence-based protocols or algorithms for commonly occurring problems of cancer patients living in the community.

Quality Evaluation

Patient Satisfaction Surveys were completed in 1995 and 1996. The Executive Director reported the implementation of an audit process primarily for quality management rather than quality assurance purposes. At the time of this investigation there were no other mechanisms in place to evaluate the quality of services provided by Interlink.

Summary

The review of program documents, administrative records and the responses provided by the *Interlink* nurses have allowed us to develop a profile of the *Interlink* program. The major features of this profile will be summarized in the following paragraphs.

The mission, vision, values and goals of the program are achieved through a combination of activities undertaken by the *Interlink* nurses across four program components. Specialized knowledge of oncology nursing and supportive care, are pre-requisite to the hiring of an *Interlink* nurse. There was evidence that this pre-requisite was being met by *Interlink* at the time of the study.

The nurses did not identify any additional formal training related to the specialized skills associated with case management beyond what they receive over the course of achieving their basic nursing and CON(C) designations.

We found that, as a group, the *Interlink* nurses place a high value on the provision of client centred care. This value guides their ability, in an independent practice model, to mobilize resources for patients and families and make linkages to those resources based on assessed needs. These activities characterize those associated with a specialized oncology case management approach (Kanter, 1989).

Client centred care appears to be a defining characteristic of the services provided by the program. The evidence

for specific structured quality evaluation and formalized tools (clinical practice guidelines, care paths, etc.) for evidence-based practice were lacking. The use of a standardized clinical pain and symptom measurement scale (McCaffery, 1992) was the one exception to this observation.

Patient Profile

The administrative data collected by the program delineated a patient profile where the majority of patients served by *Interlink* were female and over 50 years of age. They tended to have cancers of the gastrointestinal track or lungs. They had been referred to *Interlink* based on a perceived need for support, assessment or linkage to additional services and were distributed evenly across the GTA. Upon discharge from the program, they were at advanced or end-stage points of the disease trajectory.

The qualitative analysis provided additional insights into the type of patient that was served by *Interlink*. The nurses characterized the patient population as diverse. They were described as tending to be from low to moderate income brackets, socially or culturally isolated with few supports. They often have complex family dynamics, adjustment problems, complex

disease presentation, and complex treatment side effects.

Service Profile

The service profile that emerged from the program's administrative database had the following characteristics:

- Short-term, less than 2 months.
- Patient needs were systematically assessed.
- Triaging of patients prior to formalized assessment is demonstrated.
- Assessments were completed within one or two weeks of referral.
- The majority of patients referred to Interlink were already linked to the health care system prior to their initial contact with the program.
- Interlink made additional links to service providers for one third of these patients.
- Two-thirds of patients who had additional links made for them by Interlink were discharged from the program in less than six months.
- Interlink service was provided in the patients' homes.

Chapter 3

Part C: Performance Criteria of Coordinated Care

Study Objective 3: To evaluate the model of community-based specialist nursing oncology case management as represented by Interlink Community Cancer Nurses for its potential as a program to facilitate the coordination of supportive care of cancer patients in the community.

Coordination is a measure of system performance and describes a process rather than an outcome. It uses a wide range of methods aimed at maximizing three objectives: comprehensiveness, accessibility, and compatibility. At the level of direct care, service coordination is operationalized when front-line workers have a full menu of services to mobilize, to meet the needs of their patients and families, such that they experience continuity of care.

The potential of the Interlink cancer nursing program model to coordinate supportive care in the community was assessed using both quantitative and qualitative methods as described in the methods section of this report. Triangulation of methods was used to strengthen the validity and relevance of the results. An a priori framework (see Table 2, page 27) based on a theory of coordination and underlying constructs

(Alter & Hage, 1993) and normative attributes of case management (Brazil et al; Hollander & Prince, 2002) guided the development of specific criteria to focus the examination.

The results presented in this section of the report are intended to describe the coordinating functions of the *Interlink* program model categorized by the three key performance criteria: comprehensiveness of service, accessibility to needed services, and compatibility of services (Alter & Hage). These results reflect the outcome of operationalizing the performance criteria. Their theoretical definitions are described at the beginning of their respective sections.

We examined activities of the *Interlink* program identified as being associated with facilitating the coordination of care. To delineate our understanding of these activities from a number of different perspectives, we also explored the perceptions of *Interlink's* service-provider partners. Sources of data included: the

program administrative database for the 2001-2002 fiscal year (n=700); a sample of patient charts identified as having significant needs based on recorded linking activities to two or more service partners (n=113); interviews with the *Interlink* nurses using a critical incident (all nurses n=6) and the executive director), and program service partners (n=25) selected to represent a cross section of providers outside the program.

All six *Interlink* nurses responded to the respective survey and interview. The partner response rate to the personal interview was 96% and to the survey form, 85%.

Of the 26 partner respondents, five were physicians, seven were CCAC case managers (social workers or nurses), seven were nurses (community or institutional), five were social workers, and two were program coordinators (see Table 2, Appendix B). The organizations represented included hospice services, hospitals, private practices, homecare services, service brokers, and a cancer centre.

Comprehensiveness

Comprehensiveness is achieved when: all of the expertise that is needed by the patient and family is available within the system and across the continuum of care; there are enough resources to support the continuum of care; and the patient's individual differences and their needs are assessed and are responded to by the system. If there are gaps in the system of care, it becomes the responsibility of programs to undertake activities at both the administrative and operational levels to advance the development of a comprehensive system of care.

Comprehensiveness of the program in addressing the supportive care needs of patients was assessed by examining direct process of care activities of the *Interlink* nurses, referrals made to other resources external to the *Interlink* program to have supportive care needs of patients met, and their system activities in building capacity to address gaps in care.

The program logic model has identified that the *Interlink* program has a role in both providing a direct specialized oncology nursing services and a role in coordinating mobilization and linkage to resources such

that the patient and families supportive care needs are addressed. Thus for a patient to have the potential for comprehensive supportive care we expected direct care or referral to services that could address the identified patient need in the informational, psychological/emotional, social, physical, and practical domains of supportive care (Fitch, 1997).

Direct Care Specialized Oncology Nursing Activities

Data from Administrative Records and Case Report Form

Direct patient care was assessed in two ways: by reviewing the standardized assessment done on intake of a sample of 113 patient charts and through the qualitative data from the critical incident. We found through abstraction of data from the sample of patients' charts that a standardized assessment was completed with documentation of supportive care needs in all domains in over 95% of cases.

Comprehensive assessment enables a full understanding of unmet needs in all domains of supportive care that facilitates a comprehensive approach to care need. This review found unmet patient need on

entry to the program in all domains of supportive care, which are tabulated in Table 1.

In all charts there was documentation of a care plan to address the identified unmet need either through direct service provision or referral to an external agency. Chart data revealed that direct care for the most part consisted of informational and psychological support. Information support included information about cancer and treatments as well as information to support symptom management.

Table 1: *Proportions of Patients with Unmet Need on Intake (n=113)*

Need	%
Informational	79
Emotional	77
Social	58
Physical	100
Practical	55

Data from Nurse Interviews: Critical Incident

Qualitative data from the critical incident revealed that the direct care role of the *Interlink* nurses, the interventions used and the services mobilized were shaped according to the supportive care needs of the patient and factors, such as: (a) illness

presentation; (b) stage; (c) social circumstances; (d) living arrangements; and (e) availability of community services/resources upon entry into the program. Their direct care role evolved as needs changed along the cancer trajectory. Their direct care role in the provision of specialized oncology nursing support to the patient centered on: (1) managing treatment side-effects and symptoms; (2) education about what was happening to them; (3) emotional support and guidance in dealing with psychosocial issues related to the patients' and their family's response to cancer; (4) addressing survivorship issues related to employment; and (5) transitional care during the dying process. In some situations, the family was experiencing more psychosocial difficulty than the patient. Consequently, the *Interlink* nurse had focused their support in that direction. Specialized nursing support to the family encompassed activities such as: (1) informational counseling to cope with cancer diagnosis and treatment; (2) transitional care related to preparation for impending death; and (3) guidance in changing roles and relationships.

Care of the family also incorporated facilitating care of the children by accessing school based supportive care services. The *Interlink* nurses' specialized oncology nurse support role appeared to be inseparable from their role in coordinated mobilization and linkage to resources as portrayed in this statement.

"You know, we get them a doctor, set up home care, help them understand what palliative care means and to give them support through that transition and through the process of dying."

As discovered in the program logic model, *Interlink* nurses function in an independent practice model unencumbered by pre-established or conventional health agency parameters, policies and procedures. Consequently, they are able to enter the patients' home without an externally set task or agenda and are able to observe the "whole" of the patients and families experience of cancer in their own environment.

"I don't have an agenda but I'm going to go in and look for everything or anything, but with the nurse (community nurse) she's going to run the IV or look at the pain pump, or check the blood pressure, so she won't necessarily see as much as I do."

This care delivery model allows the nurses to also interact with all members of the family and any other service providers or agencies involved in care to obtain a comprehensive understanding of the supportive care needs of both the patient and family within the service context.

The ability of the *Interlink* nurses to see the whole picture provided a comprehensive understanding of the responses and reactions of patients and families to cancer and treatment that was perceived by *Interlink* nurses as helpful to the treatment center. This pattern "*Seeing the whole picture*", emerged across cases.

"You think often what's ongoing in the clinic is the kind of support the patient has at home and it may be the family, the husband's working or can't make it to clinic or there is young school age children that you don't get a chance to connect with them at the clinic...so you're not getting the whole picture of what goes on."

Data from Service Provider Partner Interviews

The importance of the *Interlink* nurse role in the provision of direct specialized

oncology nursing care was perceived by 68% of the service provider partners as either very or extremely important. Service provider partners based in cancer centres and hospitals most frequently reported *Interlink* as extremely important. Three of the four physicians interviewed saw the role as extremely or very important. A small proportion (8%) of respondents did not see the added value of the *Interlink* role.

Referral Patterns in Coordinating Mobilization and Linkage to Resources
Data from Administrative Records and Case Report Form

An analysis of the patterns of referral from the program was conducted using the administrative database. It was found that over the study period, *Interlink* nurses made referrals to services covering all domains of supportive care. In total we captured 466 referrals to an outside organization. A comprehensive listing of all referrals out of the program is located in Appendix B, Table 1.

The largest number of referrals was made to a palliative care resource (hospice, physician, or network) and the CCAC. Referrals to the CCAC largely reflected patient care needs in the physical domain. Less frequent referrals included formal and

informal community information resources (informational domain), social support agencies (social domain), emotional support services that included individual physicians (psychological /emotional), and services to support financial and legal needs (practical domain).

Analysis of direct care provision and patterns of referral, suggest that any supportive care need can be addressed directly from the program or by referral. Most direct care activity involves the informational and psychological domains. These observations indicate activities undertaken to achieve the goals of the program component, 'Coordinated Mobilization & Linkage to Resources'.

Data from Interlink Nurse Interviews:

Critical Incident

Qualitative data provided an in-depth understanding of the *Interlink* nurse activities in mobilizing resources. The pattern of service mobilization that emerged across cases could be summarized as, "*Creating a Whole System of Support Around the Patient and Family*".

From the case situations described in the critical incident, to create a "whole system of support" around the patient and family, *Interlink* nurses were continually constructing and deconstructing ad hoc care teams, titrating the services to the patient's needs.

Creating these ad hoc care teams involved getting the right combination of players in place by mobilizing services from any health care sector, such as an institution, CCAC, informal volunteer services, and professional providers.

"The biggest issue when I met her was getting to chemo. Her mother was doing the navigating at the hospital and English was not her first language but she doesn't speak English, the mother, so the stress on the mother, - it was a very long day. There were pain issues, so the palliative physician was involved as well and so I linked up with hospice. It was a visiting nurse who did a joint visit and linked up with the hospice to get the hospice volunteer to provide transportation to bring her up to her chemo appointments and be with her the whole time, which has worked out well. Then there was all the issues with the mother having some follow-up...

For instance, if a patient was either not eligible or able to access homemaking

services from the CCAC the *Interlink* nurse identified and invited other homemaking resources to become members of the ad hoc care teams to ensure the patient's practical and instrumental care needs were met. This knowledge of the service systems across the health and cancer care system was perceived as fundamental to their ability to mobilizing resources.

"Often the expertise of being in the community is needed so that we have a better sense of what the patient and family are facing, what things are there for them and what's not and how we can really maximize the support in the home."

Part of creating a comprehensive service system at the direct care level, involved informing agencies of changing needs along the cancer trajectory, working with partners to develop congruence in service goals, and shaping the *Interlink* specialized nurse role according to service context. These elements are part of the coordination construct of compatibility and will be described in further depth in that section of the results.

Data from Service Provider Partner Interviews

Service provider partners perceived that cancer patients in the community experienced enhanced supportive care when *Interlink* nurses are involved in their care. The comprehensive care provided by *Interlink* across the supportive care domains was noted in the reasons why service provider partners referred to the program. These reasons for referral are summarized in Table 2. The main reasons for referral by service provider partners were for psychosocial or information needs. In three separate interviews (two with CCAC and one hospital partner) described *Interlink* as being particularly well suited to those patients who are not eligible for CCAC services but still in need of support related to their cancer diagnosis. Partners acknowledged that *Interlink's* involvement with patients could easily change over time depending on what other services are involved and whether or not the patient identifies the need for more or less interaction with the *Interlink* nurse.

Table 2: Reason for referral to *Interlink* by service provider partners (n=25)

Psychosocial needs	13*
Informational needs	10
Newly diagnosed	7
Isolated patients	6
Case management	5
Palliative needs	4
Not eligible for CCAC	3

*Respondents were able to select more than one category

Building System Capacity to Address Gaps

We also found evidence that the activities that *Interlink* nurses engage in contribute to improving overall system comprehensiveness by identifying gaps in supportive care and participating in initiatives to address them. Four of the six *Interlink* nurses interviewed identified active involvement in addressing gaps in the supportive care system. Their activities encompassed working with formalized cancer care committees as either a member or chairperson or working with various agencies in finding solutions to service gaps. The *Interlink* nurse activities aimed at building system capacity were largely focused on

creating a system of care with a higher degree of comprehensiveness or improving accessibility to existing services. The results of these involvements were reported as: increased use of existing services, increases in service, and awareness or involvement of multi-cultural communities.

Accessibility

Accessibility is attained when all needed expertise is available to those who need it, and there are no service entry restrictions. Resources must be distributed according to a patient/family's needs rather than by structurally pre-determined rules. In addition, the system provides sufficient outreach, information, and transportation.

Accessibility was explored at the level of the program by inquiring about potential program barriers through interviews and program documents as well as studying patient flow into the program. We also considered the program's potential in facilitating access to services external to *Interlink* (referred to) and studied the patient flow patterns from *Interlink* to other linked services (referred from). The first perspective looks at the ability of patients to

access the services and supports specific to the *Interlink* program. The second is related to those activities that the *Interlink* nurses undertake to support patients and families to gain access to needed services in the broader system.

Data from Administrative Record and Case Report Form

As previously described in the service profile summarized in the Program Description, Chapter 3, Part C of this report, the *Interlink* program provided service to patients across the illness trajectory. In addition, patients were from various age groups and types of cancer populations.

An analysis of program documents revealed no obvious barriers to accessing the program. The program's only eligibility criterion was that the patient is an adult living with cancer. Of particular interest, there was no restriction on referral source (care provider, patient, or family member). Transportation or other physical barriers to the program were not in evidence since all initial full assessments that were completed were done in patients' own homes in all areas of the GTA.

From the sample of 113 case records that were reviewed in depth, the nurses contacted 97.9% of cases within seven days of receipt of the referral and 83% of patients had a full assessment completed within 14 days of the case being opened.

Data from Interlink Nurse Interviews

In relation to access to the program, the *Interlink* nurses expressed concern that the program was not reaching all of its target population. The *Interlink* nurses noted that specific patient populations such as those newly diagnosed and those with hematological cancers are often not referred. In addition, *Interlink* nurses expressed concerns that patients were not being referred in a "timely manner".

"Well we get a lot of people late so we know that there was a whole wad of them out there that were out there struggling and when we talk to them we think only if I had known about you before".

When asked to speculate about reasons that these referrals were not being made in a "timely" fashion the *Interlink* nurses perceived that there is a lack of understanding of community services overall and specifically of the role of Interlink. More importantly, they identified a

“...people are getting lost a little bit because often I’ve heard patients say ‘I wish I knew about you sooner, why wasn’t I told.’ Or a pamphlet is just sort of shoved into a binder and it gets lost and it’s just one of many resources that’s in there that the person may not look at or is too overwhelmed to look at and they don’t realize what we are able to do and how we can help.”

lack of recognition by providers when patients/families are experiencing problems in adjusting to cancer and its treatments.

“I have seen these patients in my case load who are so compliant, so good, so quiet, so not trouble, so that nursing is not going to notice that this person is particularly having a difficult time because they are not saying they are. If there is a disaster at home, they (clinic nurses) are not going to know, why would they tell that to the nurse in the clinic”.

Data from Service Provider Partners

One-third of service provider partners (36%) did not perceive that there were barriers to the *Interlink* Program. An equal number (36%) identified that lack of awareness about the program was an access barrier.

Service provider partners also identified the geographic boundaries of *Interlink* as a barrier (32%) to the program since they were able to access *Interlink* for some of their clients whereas other clients were not able to access the service. For instance, cancer centers whose referral source extends beyond the GTA would only have access to *Interlink* for their clients who reside in the GTA and not those in other areas of the province. A small percentage of service provider partners (16%) expressed concern that the *Interlink* nurses were all English speaking as a barrier to the program even though patients’ access is not restricted by ethnicity and translation services are utilized by the program.

Access to Services External to the Interlink Program

Data from Administrative Records and Case Report Form

To measure the program’s performance in facilitating access to other service providers in the community we analyzed the transition and follow-up of patients who are referred to other care providers (linking activity). This data also comes from the 113 patient charts that were reviewed in depth. In over two-thirds of cases (70%), where it was identified that a link needed to be made to an outside service provider, there was

documentation in the patient chart of follow-up to this to ensure that the link was successfully made. When reviewing this in more depth, we became aware that this data may not be completely accurate in that not all follow up activity is documented in the patient's file so that this is likely an underestimation. We were not able to accurately analyze the time lapse between referral and confirmation as the latter was not recorded systematically within a defined time period and in many cases was recorded well after the link had been established.

Data from Interlink Nurse Interviews:

Critical Incident

Qualitative data obtained from the critical incidents revealed that *Interlink* nurses crossed traditional sectoral boundaries between institutional and community care services in order to access services necessary to having patient and family needs addressed. Two specific activities labeled as *Boundary Spanning* and *System Navigation & Advocacy* were used to summarize the activities undertaken by *Interlink* nurses to facilitate access to

supportive care services across health and cancer care systems.

Boundary spanning appeared to be critical in accessing needed services wherever they existed in the system and to ensure that patients/families would not fall in the cracks in the system. An example of boundary spanning to prevent the patient from falling through the cracks in the system is portrayed in the following statement:

"I phoned her coordinator today because there were no orders given about the Hickman line, so I had to sort of organize that this morning. I think she's two days post-op and nothing had been ordered. I guess her coordinator is off so it wasn't getting done, so I called the person who was covering her and got them to fax in some orders or at least on his end get things worked out."

In another scenario, the *Interlink* nurse found that the community within which the patient lived was not providing the specialized palliative care services that the institutional providers assumed were in place. Consequently, the patient had ongoing symptom issues that required further investigation in the institutional sector.

“I was instrumental in getting somebody to finally pay attention to this man, just because he had his lymphoma for a long time didn’t mean that it was time to say goodbye to him especially when he needed symptom management and the specialists were saying, “well we don’t have anything to do with your heart disease, I don’t have anything to do with your asthma, so go to your family doctor”, so there was just nobody coordinating the medical care of this fellow.”

In some situations they worked to influence service access by communicating their specialized knowledge about the anticipated needs of the patient and family across the cancer trajectory.

“I think I am able to influence explaining around this type of protocol this is what we can anticipate and expect, this is going to be very difficult and things are going to get more challenging we need to be able to have the supports...helping them to understand how multifaceted the cancer experience is”.

The *Interlink* nurses’ knowledge of community services enabled them to navigate through a confusing service

system accessing resources to create a comprehensive system of support around the patient and family that was customized to their needs across the cancer trajectory. This ability was portrayed as an important skill and role of the *Interlink* nurse, described by the program’s executive director. Navigating the system involved accessing care support wherever it existed in the system. This role was perceived by *Interlink* nurses as coordination and valued by patients.

“I use the word navigate.... Like they are taking a disjointed complicated system and trying to make it as simplistic as possible for individuals when all the individuals need a different piece of that system”.

The *Interlink* nurses knowledge of community resources combined with their advocacy skills appeared to facilitate access to needed services.

“We’ve learned advocacy as well so that we can be quite assertive so that if it’s not working one way we will try different options and persist and generally that’s worked well for us.”

“They think that the *Interlink* role is so valuable because you have helped them to navigate the system and retain I think a semblance of not so much coordination, well it is coordination but it’s also just a journey with, whereas you started off in one area and then maybe flipped back and forth, which is part of the system, that they keep getting introduced to new players.”

Data from Service Provider Partner Interviews

Almost half of the service provider partners interviewed (48%) identified the *Interlink* nurses knowledge of the community resources as an important service access role of the *Interlink* program. Service provider partners also identified that the linking (36%) and advocacy (32%) activities of the *Interlink* program were important. In addition, being able to access the program’s resources related to: expertise in cancer care (32%); patient education (28%); counselling (28%); coordination (24%); and provision of comprehensive assessment (24%) were valued.

Compatibility

Compatibility is maximized when all the service providers involved with the patient share the same goals of care and these goals are congruent with the patients’ needs, goals & wishes; a client is treated consistently from one component of care to another such that there is a shared plan of care and services are sequenced as the client needs them.

Compatibility is demonstrated when a variety of care providers effectively share information about clients and are able to maintain collaborative relationships. Compatibility was evaluated in the study by examining: information sharing between programs; shared care planning; and congruence between *Interlink* program activities and those of other service provider agencies. Data regarding compatibility was obtained primarily from two data sources: *Interlink* nurse interviews using critical incident methodology and Service provider partner interviews. Client centered care is foundational to achieving care compatibility. Client centered care was specifically examined by evaluating congruence between service provider partner program

goals and *Interlink* program goals. In addition, *Interlink* nurses were asked specifically about their activities to achieve client centered care in the critical incident.

Data from Administrative Record and Case Report Form

Evidence of *Interlink* working with others comes from the review of the in-depth patient charts (n=113) where in 97% of the cases at least one other care provider was documented to be providing service concurrently with *Interlink*.

Data from Interlink Nurse Interviews: Critical Incident

The qualitative data in critical incidents revealed that *Interlink* nurses used a variety of strategies, such as joint visiting and continuous dialogue /communication through telephone or voicemail systems to promote the development of shared goals of care among service providers. *Interlink*

nurses took on a role of informing the ad hoc care team members of the identified patient needs and goals and the role each member might play in addressing these issues.

It appeared that the *Interlink* nurses' continuous assessment, reassessment, and anticipation of the patient and family needs was critical to ensuring that membership of the ad hoc care team provided support services that were relevant and appropriate to patients' changing needs.

"Identifying the needs calling in the people and then reassessing the needs as she moved along. Then keeping in touch with all the players. So it's sort of going in assessing it, reassessing it, keeping in touch with all the players to see how they're assessing it, what they are doing, how the plan is changing as she's changing."

Further the specific wishes and goals of the patient appeared to influence the nature of the dialogue between *Interlink* and other providers The *Interlink* nurse characterized this balancing of goals between services and patients as a kind of "dance".

“So often our dance is just that, its recognizing in our words we have to be very sensitive to what the needs are or you run the risk of severing the relationship, of not being invited back if you push too hard.”

Interlink nurses continually shaped their role according to the needs of the patient and the strengths or weaknesses of the existing service system. For instance if the community nurse was addressing physical care needs they shaped their role to address the emotional needs.

“So I went in and it seemed there were a lot of physical needs and nobody was addressing at all the emotional needs.”

The *Interlink* nurse role changed as other providers became involved. *Interlink* nurses appeared to assume a coordinating role in some situations to ensure that the ad hoc team included a comprehensive range of services as defined by the patient’s needs, if no one else was available to take on that role.

In situations where a designated case manager was involved in the ad hoc service team, the *Interlink* nurses’ role was reshaped. In some situations,

the *Interlink* nurse became a patch where resources were not available to address unmet supportive care needs.

“...there are pockets of metro that don’t have very good care services and so the *Interlink* nurse is very useful working with the family physician and oncologist even, because there is just no palliative physician, those services are difficult in some pockets.”

The breadth of their role in these situations encompassed care not only during the treatment period but also extended into survivorship issues.

“So when I came in she was just finishing her treatment but everyone had left, she didn’t have anyone left anymore, it was just *Interlink* coming. I guess they saw that she was finishing and she was doing well, everyone kept saying ‘you’re doing great, and then she couldn’t find a job, she wanted to work and her welfare cheques were stopping. I promoted self-sufficiency ‘focused her on what she needed to do’”

In some situations, as the patient and families gained the resources required to meet their needs, their role became redundant. Subsequently they either

withdrew or took on a new shape to address other needs as they surfaced.

Interlink nurses also expressed the belief that their service provider partners changed their plans of cares based on the information that the nurse provided to them. While the nurses offered a number of reasons for why they felt that their information had this impact, the most consistently expressed was the perceived ‘credibility’ and the reputation that *Interlink* has for its knowledgeable practitioners with expertise in oncology.

“...this girl needed to have peripheral IV, she was going poorly and she needed to have fluids in the home so they did it but I don’t think they realized what a hard time she had with peripheral IV’s and it’s horrible and she was starting to refuse. I just sort of saw this domino effect going to happen with her and she’s on this salvage treatment for her chemo and she would have to mend transplant and then she would have more chemo and it was sort of the beginning of it and if things started failing I just didn’t see it going anywhere. So I talked with the coordinator and I asked if she could arrange to have a Hickman or a port or something put in sooner than later, they were going to do it I think in January... I called this week and she had it put in already.”

Recognizing that building and sustaining collaborative relationships required an investment apart from specific patient care, *Interlink* nurses reported seeking more formal mechanisms for developing relationships with providers in the system by contributing to intra-organizational committees aimed at improving the system of care to cancer patients and their families. The relationships that developed over time through shared activity were perceived by

“It’s the credibility that’s been built over time around the expert role of the oncology specialist nurse in the community. It’s base on past experience of working with individual families....So when we call in, for example, the CCAC community care access and give an assessment I’m known in the community as well as respected in terms of opinion. I think the other piece about oncology is that we know that the most expert assessment is the one that’s just been done. It doesn’t really matter if the case manager was out there ten days ago the situation has changed and so we are communicating that clearly, concisely what level of service is now needed based on what we are observing.”

the *Interlink* nurses as critical to the sense of cooperation and collaboration between agencies. Ultimately this contributed to their

ability to jointly provide services that were compatible with patients' needs.

Only one nurse identified tensions between the program and other providers. This tension occurred when a designated CCAC coordinator perceived that the *Interlink* nurse was telling them what to do.

“The coordinator she was the one that, well she thought that she was the coordinator and that she was in charge of everything, so she had a nurse in there and she had equipment in there and she would listen to me but she was very reluctant to take my

In partner interviews we specifically asked about satisfaction with information exchange with *Interlink*. Twenty-one of the twenty five responding partners completed a short answer information survey to gather additional detail about the communication patterns and working relationships that exist with *Interlink*. Over two-thirds of the respondents were satisfied with how information is exchanged between their organization and *Interlink*. No one

Table 3: *Information Provided by Interlink to Service Partners*

	Yes	No	No Data
Information Needs	21/25 (84%)	3/25 (12%)	1/25 (4%)
Emotional Needs	23/25 (92%)	1/25 (4%)	1/25 (4%)
Social/Spiritual	21/25 (84%)	3/25 (12%)	1/25 (4%)
Physical Needs	22/25 (88%)	2/25 (8%)	1/25 (4%)
Practical Needs	23/25 (92%)	1/25 (4%)	1/25 (4%)

Data from Service Provider Partner Interviews

Interviews with service partners provided confirmation of the notion that *Interlink* provides a consistent source of information when the patient moves from the community to the hospital and back. This continuity enables all the community care providers with the opportunity to stay connected to the patient in a more seamless way since someone on the community team can relay information about assessments and care plans between the institution and the home setting.

service provider type was more likely to state they were not satisfied with how information was exchanged. The majority (81%) were at least moderately satisfied with the ongoing communication and

sharing of information between their organization and Interlink, whereas 38% of those were highly satisfied. To further explore this we asked partners about information exchange specifically around needs of patients and within domains of supportive care. We asked partners “When you serve patients as part of an inter-agency team that include Interlink, do you receive information from Interlink about the needs of the patient or family?” Ninety-six percent of respondents indicated that they did.

We went on to inquire “Of the information that you require to make decisions about the services you provide, which type of information is Interlink able to provide to you?” the results are listed in Table 3, demonstrating that information sharing was high within all domains of supportive care.

Despite these high levels of information exchange there were concerns expressed about the mostly verbal and informal mechanism that were used. Nevertheless, the patient assessment information shared by *Interlink* was perceived to be comprehensive and of a high quality. Eighty-eight percent of service partners

indicated that they used the patient information provided by *Interlink* to plan care.

We found a high concordance between Interlink and partners regarding their perceptions of Interlink nurses’ role. Service provider partners indicated that Interlink nurses continued to add value to patient care even when multiple service providers were involved. Their compatibility in these situations appeared to be related to their roles in the following areas by their service provider partners: providing consistent information to service provider partners (52%), ongoing monitoring of the patient (40%), pain and symptom management (28%), coordinating care (24%), advocating for services (24%), and ongoing assessment (20%).

We asked service provider partners to identify the importance of the *Interlink* nurse role in providing specialized oncology nurse care to patients and families. Two-thirds of respondents (68%) saw the *Interlink* nurse role as either extremely or very important. One quarter (24%) of those interviewed felt the role was somewhat important. Four percent did not consider the role as important. Service provider partners were asked to describe their reasons for evaluating the role of *Interlink* as important

or less important. Service provider described *Interlink* as a “consistent seamless touchstone” bridging the gap between institutional and community based care and their ability to move back and forth between these systems was considered important. As patients became more palliative the need for *Interlink* appeared to become less important depending on whether comprehensive palliative care was available.

One-third of respondents indicated occasional tension within the inter agency teams in care of complex cases, mostly resulting from confusion and lack of clear definition of who was coordinating overall care. Most of the respondents who suggested this acknowledged that a lack of full service integration and role definition within the system of care was the major contributor and that it was not a manifestation of individual inter agency issues.

Client Centered Care

The home setting for care is uniquely different from care in the institutional setting, since the patient and family are in control of who

ultimately enters this care setting and decides the goals they wish to have providers address. The construct ‘client centredness’ is foundational to the theoretical framework of coordination (Alter & Hage, 1993). As our results have shown, it repeatedly emerged as a theme in our conversations with *Interlink* nurses related to their activities.

Since the *Interlink* program is delivered in the patient/families home, the program model has adopted a client centered empowerment model of care delivery (Howell & Jackson, 1999). The *Interlink* nurse portrayed the creation of a patient/family-centered system of supportive care customized to their needs and goals as foundational to the supportive care role they assumed. This was described in the statement: that follows.

“I mean everything goes through the patient and she’s making all the decisions herself, we’re just sort of telling her what the options are but she’s making the decisions. ‘She needs to know that she’s the one in control and that a lot of times what I’m doing is reinforcing what her stated goal is, and that I am trying to help her reach this.”

Data from Service Provider Partners
Interviews

Finally, almost all respondents reported incorporating a client centred approach to care (96%) that was congruent with the *Interlink* core values of care. This general observation supports the notion that members of the ad hoc care team share values with respect to the goals of care. All care partners indicated awareness of the particularly strong client centred focus of care by the *Interlink* program and felt it was a unique and valued characteristic of the *Interlink* program.

Chapter 4

Discussion and Recommendations for Decision-Makers

Our study of specialized case management in general and Interlink as a specific example in the current Ontario health care context provides empirical evidence about the potential of this type of program to address gaps in coordination of SCC in Ontario.

The importance of providing coordination of care and supportive care services for cancer patients whose needs are frequently complex has widespread acceptance in our current health care system (Lauria, 1991). It is anticipated that improved coordination will result in improved patient and family satisfaction, a reduction in psychological problems, fewer emergency care visits, increased patient compliance to treatment regimes, and more timely care for problems (Institute of Medicine, 1996; Starfield, 1992). The need for improved coordination of supportive care for cancer patients is identified in numerous patient-need assessment surveys conducted in Ontario and other parts of Canada (Ashbury, Findlay, Reynolds, & McKerralehen, 1998; Canadian Cancer Society, 2003). This is also identified as a priority in the Report

of the Cancer Services Implementation Committee (Hudson, 2001) prepared for Cancer Care Ontario, which notes the need for improved access and easier navigation of the available services.

Most of the SCC services are provided by different generalist agencies working independently rather than as components of a coordinated system with SCC as its primary focus. Thus, at least two major discontinuities in care exist. One between treatment centers and supportive care services and the other between different SCC providers in the community. The result of these discontinuities is limited effectiveness of SCC services and poor continuity of care from the patient's perspective (Canadian Cancer Society, 2003).

The expectation is that community providers (e.g., family physicians or surgeons), who receive little training to deal with the multiple and complex needs of cancer patients, could contribute to improved coordination of care (MOHLTC, 2001; Provincial Cancer Network, 1995). In our coordination of care study (Sussman et al., 2003), these providers were found to be

uncomfortable in this role and unlikely to change their practice.

An accumulating body of health research suggests that improvement in coordination of service delivery requires interventions not only at the system level (e.g., networks), but also at the direct patient level (Canadian Breast Cancer Initiative, 2002; Hollander & Prince, 2002). Specialized oncology nursing case management is one model that is identified in Canada and internationally as a potential direct patient level solution for addressing the existing fragmentation in supportive care (Canadian Breast Cancer Initiative, 2002). The present lack of empirical evidence makes it difficult to develop policies.

The aim of this study is to provide the evidence necessary for decision makers to consider in the development of such policies. The investigative team presents recommendations based on the results of a review of the literature of effectiveness of case management in oncology and an in depth case study of the Interlink program.

A systematic review of the literature on the impact of specialized case management on patient outcomes,

reveals that existing studies are of poor quality comprised mainly of single cohort descriptive studies without a comparison control group and a high probability of selection bias. Outcome measures in the studies are diverse, care models and care contexts are not comparable making results difficult to interpret due to heterogeneity of populations and interventions. One observation is that models with direct care of patients as opposed to those without direct care tend to show patient benefit. Symptom specific interventions may result in short term improvements in specific patient outcomes but not overall supportive care, suggesting interventions that address multiple supportive care domains are required.

Important outcomes to examine may include measures of supportive care needs, quality of life and continuity of care. The former captures the domains of supportive care while the latter are expected to improve for patients who receive care coordination. Earlier intervention is supported by the literature review that suggests the greatest benefits may be in early diagnosis prior to contact with organized cancer services (i.e., regional cancer

centre or hospital with specialized cancer program).

Our case study of the *Interlink* adult program reveals that it is fully implemented in all regions of the GTA. The *Interlink* program demonstrates linkages with institutions, networks, and individual practitioners in all regions of practice. It also serves all patients with cancer at all points in the care trajectory with no restrictions. However, we find the majority of patients in the program tend to be at the latter part of the care trajectory. Sixteen percent of the new patients are categorized as being in the early stage. The majority of referrals come from hospitals, self-referrals, and Community Care Access Centres. *Interlink* involvement in patient care appears to be of relatively short but intense duration (the majority of patients are in the program for two to six months) with a mean of two home or institutional visits and seven telephone calls per new patient/family.

Examination of the program's administrative databases generates evidence that care is provided to 700 new patients by the program's 6 nurses giving an average of 120 new patients

per nurse during the twelve-month study period.

In depth understanding of *Interlink's* model structure and functioning leads to development of a logic model with four major program components: Specialized Oncology and Supportive Care, Coordinated Mobilization and Linkage to Resources, Community-based Education and Research, and Community Resource Development. These four components are expected to effect changes at patient, family, and system levels. The program identifies the need to become involved earlier in the cancer care trajectory. At the same time a lack of awareness in the community creates a potential barrier to access, especially for the early diagnosed.

Our assessment of quantitative and qualitative data within the theoretical framework of coordination reveals that the *Interlink* model demonstrates activities that promote the coordination of SCC in the community.

Comprehensive care is demonstrated by assessment in all domains of supportive care and direct care, primarily in the informational and psychological domains with referral to

services or providers in all other domains of supportive care. We find that patients cared for by *Interlink* have the potential to link to virtually any service in any sector to address their needs. There is some potential to facilitate coordination at this level demonstrated by activities that the program is involved in at the system level to help improve system capacity (through advocacy activities) and reduce care gaps (through education and support of generalist providers). Finally, the *Interlink* nurses provide a community resource for generalist practitioners and facilitate system level comprehensiveness of care by enhancing the potential to care for cancer patients by practitioners who lack specialized oncology expertise.

Accessibility to the program is demonstrated by the absence of significant barriers to the program based on analysis of program documents and processes of care. We find that patients referred in to the program have prompt intake and assessment of needs. Further, it is found that the model facilitates access to other needed providers in the system of care by close follow up of referrals (i.e., links) made

through the program. Our in depth analysis of charts reveals that in 70% of cases, where a referral to another provider is made by *Interlink*, there is evidence of follow up to ensure that the linkage is made. Service partners do identify some limitations in awareness of the program and some geographic limitations but feel overall that the program itself is accessible and facilitates access to other providers in the community.

Compatibility is demonstrated by the use of standardized assessments that captures all domains of supportive care need in over 95% of charts examined in our chart review. This, coupled with the client centred approach that is the foundation of program care delivery, ensures that supportive care for cancer patients have the potential to be compatible with their individual needs and circumstances. A consistent message from service partners is that *Interlink* is unique in its client centred approach and that the program has an effect on their approach to patient care. This reinforces the notion that *Interlink* has the potential for contributing to the enhancement of service compatibility

within the community to meet patients needs and goals of care.

From the perspective of information exchange to facilitate compatibility we find a high level of satisfaction between *Interlink* and service provider partners. Service partners identify one potential limitation and suggest that written communication about patient issues would improve their ability to deliver care although it is recognized that this may actually have detrimental effects on efficiency and with current *Interlink* program resources this may not be possible.

Little tension is described in interactions between *Interlink* and its service partners in the care of patients further supporting the compatibility of *Interlink* with other care providers in the system of care.

During the course of our inquiry we became aware that the *Interlink* program, through its various components is providing care that includes many aspects of case management and went beyond this model of practice. Many of the characteristics of case management that were identified a priori as important are found to be present in the current

model. Nevertheless, two characteristics are identified as requiring additional attention. We find that the use of evidence-based care paths is limited and quality assurance activities are not being undertaken consistently. Both of these concerns represent areas of growth across the entire health care sector. Continuing to evolve these areas will add strength to the model.

Case management often involves the brokerage of services based on assessment of need, rules of eligibility, and available resources. By way of contrast, the *Interlink* model incorporates direct patient care and referral that are guided by patient need only and do not involve brokerage nor restrict access to a set of contracted care partners.

A significant advantage of the *Interlink* model is that it provides unrestricted coordination of care to address patient care need. Service partners identify the *Interlink* program as adding value to the current care system. This is also observed in an examination of the processes of care where activities termed “patching and bridging” that represent the addition of support in

times of service deficit and pulling back to limit duplication.

The strengths of this study include; the use of a mixed method approach, multiple data sources to address the research objectives, and input from the project consultation group.

Use of qualitative and quantitative data sources allowed us to develop converging lines of inquiry and triangulation of observations. Quantitative data assists in delineating the outputs of the *Interlink* program. Qualitative data places these outputs within their context and describes the activities that *Interlink* undertakes to achieve its goals. Replication of outcomes in other care settings will require an in-depth understanding of structures and processes of care to inform the decisions of policy makers. Engaging members of the Project Consultation Group contributes to the development of our evaluative template and research approach and ensures that findings are meaningful to a range of stakeholders.

Despite these strengths, it is important to acknowledge study limitations. The study setting is limited to the Greater Toronto Area as the adult

program is yet to be implemented in other communities in Ontario. The GTA represents a significant proportion of the cancer burden in the province (estimated at 30% to 40%) and the greatest diversity among patients and providers. Nevertheless, findings in this diverse urban setting may not be fully generalizable to rural and isolated communities.

Another limitation comes with the use of administrative databases. It is well known that this type of data may be limited due to accuracy and recording inconsistencies that are a reflection of the purpose of the database rather than inherent deficits. For example, the use of the database to enumerate assessments in the study was found to under represent the true level of assessment of patients by the program, as determined by a supplementary chart review process.

This study generates a clear understanding of the *Interlink* model of care and its coordination function. The *Interlink* program is unique. This model appears to have the potential to reduce gaps in coordination of supportive cancer care at the operational level. The results of this study are important to

decision-makers who are interested in improving supportive cancer care in the province of Ontario.

Ultimately the patients' experiences and perceptions must be considered in determining the impact of health care interventions. This should be the focus of future research.

Recommendations for Decision Makers

This study has explored the effectiveness of a model of care as represented by the *Interlink* program in the coordination of supportive care for cancer patients in the community at the operational level. Based on our study findings, the investigative team presents the following recommendations for consideration in the evolution of policy decision-making.

1. *Community based specialized nursing as represented by the Interlink nursing cancer care model should be considered for more wide spread deployment in the Province of Ontario as a direct patient care intervention to address regional gaps in coordination of supportive cancer care.*

This study finds that this model of specialized oncology nursing addresses key gaps in SCC in the community through direct provision and coordination of SCC services. Each region in Ontario has different strengths and needs. The flexibility and responsiveness of the models structure would facilitate its adaptation to the unique needs and strengths of each region.

If such a model is considered for more widespread deployment, policymakers will need to consider a number of prerequisites to ensure success and sustainability: 1) Stable funding, 2) Appropriate case loads, and 3) Minimum standards for adequate training.

Stable funding will provide the necessary support to enable more resources to be put directly towards improving SCC in the community in all regions of the province through direct care and system building activities that would include joint planning and supporting generalist providers in the community.

To maintain the model's coordination potential, caseloads targeted at 50 to 65 patients at any one time per FTE or

approximately 120 new cases per year/ FTE is recommended. These estimates are based on our observations of the current service delivery profile that appeared to accommodate adequate care without significant waiting times for referrals into the program. Further research is necessary to better define which populations of patients would derive the most benefit from this model of coordination of care to assist with planning at the regional and provincial levels.

Nurses working within the model should have adequate training to meet minimum Canadian Association of Nursing in Oncology standards for content knowledge and may require advanced practice skills that would need to be negotiated within each region with appropriate planning bodies. More widespread deployment of specialized oncology nurses as represented by the *Interlink* model will be dependant upon access to specialized oncology nurse preparation and current professional education programs.

2. *The Interlink model should become more integrated with*

existing cancer and community care systems within each region.

Integration of the model is important to ensure clarity of roles and minimization of incompatibility between service providers. Integration will also facilitate access by reducing the lack of awareness that we found in our study of the model. Integration will also support the use of common assessment tools and information systems that will further enhance coordination of care.

Integration of information systems will facilitate the development of reliable common indicators to monitor quality of care. Shared information systems that include accurate staging information, patient demographics, and treatments are important to monitor system performance and provide data to support ongoing development of program and planning activities that are responsive to needs within each region.

Integration will also facilitate the ability to develop evidence based nursing interventions by giving access to resources that are already in existence provincially and at the regional level.

Finally, service integration is important to address the need for

improved linkages between institutions and the community that has been identified as a priority in the new regional models of cancer care (Cancer Care Ontario, 2004).

3. *The model should remain community based.*

One of the significant strengths of the *Interlink* model is the fact that it is based in the community and coordinated care in this setting through direct provision as well as linking and referral to other service providers. This is important given that most supportive care is currently delivered in the community by a number of different generalist providers. In our study we found that *Interlink* facilitated a client-centered approach by all providers. Further *Interlink* serves as a specialized cancer knowledge resource in the community that supports other generalist care providers. Deployment in the community would potentially help overcome the ongoing deficiencies in human resources within communities by supporting generalist providers in caring for cancer patients.

4. *Further research should focus on patient supportive care outcomes.*

The results of this study have demonstrated the potential for the coordination function of a nursing model as represented by the *Interlink* program in the GTA. It is assumed based on our findings of program activities that patients and their families will experience improvements in continuity of care, having supportive care needs met, satisfaction, and quality of life. Although the empirical data that we have presented make a strong argument to support the use of this type of model of care, it would be important to confirm this with patient outcomes using rigorous methodology, given the mixed results that were found in the review of the literature. Combined with what has been observed about the coordination function of this care model, having patient supportive care outcomes to complement our findings would make a significant contribution to the literature and provide important information to decision makers provincially, nationally, and at the international level.

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Appendix A

Table 1: Randomized control trials

Author (year)	Setting (N)	Grade	Intervention	Patient	Outcomes	Program/System
<p>Addington-Hall et al. (1992)</p> <p>Raftery, Addington-Hall, MacDonald, Anderson, & Bland (1996)</p> <p>[companion studies]</p>	<p>London, U.K. (N=554 Patients)</p> <p>Cancer Type: 13% breast, 23% lung, 21% colorectal, 12% prostate</p> <p>Illness stage: End (prognosis of less than one year to live)</p>	lb	Community based nurse coordinator to assess patient need and coordinate care needed (no counselling provided by nurse).	<p><u>Sources:</u> Patient and carers' structured interviews measuring the presence and severity of physical symptoms, ADLs, sources of supports, psychiatric morbidity (Hospital Anxiety and Depression Scale), use of and satisfaction with services, and social support (Apgar scale). Carers' QOL, satisfaction with services, and problems with caring for patient also measured. Patients were interviewed at baseline and at intervals from two weeks to six months (severity dependant). Carers were interviewed eight weeks after bereavement.</p> <p>Few differences found between intervention and control group – time of death, satisfaction with services, patient quality of life, patient depression, carer depression, reported health of carer were similar between groups.</p> <p>Physical symptoms (14 types examined): Intervention group patients were less likely to suffer from vomiting, were more likely to report effective treatment for it, and less likely to be concerned about having itchy skin. Their carers were more likely to report that in the last week of life the patient had had a cough and had had effective treatment for constipation, and they were less likely to rate the patient's difficulty swallowing as severe or to report effective treatment for anxiety. Coordination group patients were more likely to have seen a chiroprapist and their carers were more likely to have contacted a specialist nurse in a nighttime emergency.</p> <p>Carers in the intervention group were less likely to feel angry about the death of the patient.</p>	<p><u>Sources:</u> Service usage data (admissions, inpatient days, outpatient attendances, and home visits), cost admin data, costs to patients collected by structured interview.</p> <p>No differences in costs to patients found (no data presented on costs to patient). The mean total costs incurred by the intervention group were significantly less than those of the control group. The intervention group used significantly fewer inpatient days and nurse home visits; no difference was found in use of GP, social worker, or practical services between groups. Mean cost per coordinated patient was almost half that of the control group patients (£4774 versus £8034).</p>	
Moore et al. (2002)	<p>U.K. – 3 sites Southeast England (N=203 Patients; 144 GPs)</p> <p>Cancer Type: Lung, cancer</p> <p>Illness stage: Various (expected to survive at least three months)</p>	lb	Clinic based nurse specialist providing patients with information, support, and coordinated communication with other services.	<p><u>Sources:</u> Mail survey questionnaires at baseline, 3, 6, and 12 months, measuring EORTC (QOL-14 items) and patient satisfaction (5 items). Admin data on patient survival.</p> <p>No difference in EORTC between intervention and control group except on one item at three months (i.e., dyspnoea lower in intervention group).</p> <p>Patient satisfaction was high overall, significantly higher on all items in intervention group at 3 months and on most items at 6 and 12 months.</p> <p>No difference in time of death between groups.</p>	<p><u>Sources:</u> Mail survey on satisfaction of patients' physicians, admin cost data.</p> <p>No difference in MD satisfaction.</p> <p>No difference in cost of care (not including cost of intervention).</p>	

Table 1 cont.: *Randomized control trials*

Author (year)	Setting (N)	Grade	Intervention	Patient Outcomes	Program/System
Mor, Wool, Guadagnoli, & Allen (1995)	Rhode Island, USA (N=259 Patients) Cancer Type: 40% breast, 10% lung, 16% colorectal, 12% lymphoma Illness stage: 12% curative, 25% adjuvant, 61% palliative	Ic	Community based nurse case manager providing information, linkage to needed services, and monitoring through an initial home visit, needs assessment, development of an intervention plan, follow-up phase, and termination visit.	<u>Sources:</u> Structured telephone interviews with patients at baseline, three months, and six months, measuring 1) unmet needs, 2) symptom severity, 3) Quality of Life Index (9 items), 4) Mental SF-36 (5 items), and 5) specially developed questions about treatment disruption (4 items). At baseline, patients were classified into three strata for analysis: Actual unmet need, predicted unmet need, low risk for unmet need (approximately equally sized groups). No significant differences found between intervention and control group on any measures. At three and six months overall prevalence of unmet needs was low (having decreasing in both groups from baseline).	None
Rawl et al. (2002)	Two Midwestern sites, USA (N=109 Patients) Cancer Type: 51% breast, 23% colon, 27% lung Illness stage: Newly diagnosed and receiving chemotherapy	Ib	Clinic based nurse specialist providing patients with information on symptom management, education about disease and treatment, and emotional support, in addition to coordinating medical resources.	<u>Sources:</u> Structured telephone interviews at baseline, halfway through intervention (nine weeks), and one month post intervention (24 weeks), using 1) Medical Outcomes Study 36 Short Form (SF-36), 2) Centers for Epidemiological Studies Depression 20 scale (CESD-20), and 3) State-Trait Anxiety Inventory (STAI). SF-36: Participants' psychosocial functioning improved over time, regardless of group assignment. None of the functional outcomes showed a significant intervention effect. CESD-20: Intervention group significantly improved (i.e., had lower depression scores) from baseline to nine weeks (mid point) compared to control group, although no significant difference occurred over total duration. STAI: Intervention did not appear to have a significant effect on anxiety.	None

Table 1 cont.: Randomized control trials

Author (year)	Setting (N)	Grade	Intervention	Outcomes	
				Patient	Program/System
Ritz et al. (2000)	Midwestern, USA (N=210) Cancer Type: Breast cancer Illness stage: Newly diagnosed	Ic	Community based APN interventions provided through clinic, hospital, telephone, and homecare visits. Interventions include assessment, diagnosis, outcome identification, planning, coordination, symptom management, patient health education, consultation, and research.	<p><u>Sources:</u> Self-administered structured questionnaires using 1) Mishel Uncertainty in Illness Scale (MUIS), 2) Profile of Mood States (POMS), and 3) Functional Assessment of Cancer Therapy (FACT-B), at seven intervals over two years.</p> <p>MUIS score decreased slightly for both groups, no change seen in POMS and FACT-B scales.</p> <p>MUIS: Uncertainty was significantly lower in the intervention group than the control group at 1 month, 3 months, and 6 months, but not at 12 months. In addition, uncertainty increased significantly at one month following baseline in the control group but not in the intervention group.</p> <p>POMS: Intervention and control groups did not differ significantly on scores.</p> <p>FACT-B: Intervention and control groups did not differ significantly on scores.</p>	<p><u>Sources:</u> Cost data (charges and reimbursements) were collected from hospital and clinic billing systems for two years after the date of diagnosis for each participant. Clinic reimbursements were calculated by multiplying clinic charges by a collection factor, i.e., net revenue received from a participant's insurance divided by the gross charges assessed to this insurance.</p> <p>Overall costs: No significant differences existed between intervention and control groups in either overall charges or reimbursements or those categorized by source (inpatient, outpatient/clinic, home care, emergency room/urgent care). Overall, APN mean time per patient was 1377 minutes, for a mean cost of \$629 (USD) per patient. Seventy-five percent of APN time (and cost) occurred during either clinic or telephone visits. APN time per patient was greatest (746 minutes) during the first six months, dropped substantially in the second and third six-month periods (301 and 170 minutes, respectively), and was least (159 minutes per patient) during the last six months.</p>

Table 1 cont.: *Randomized control trials*

Author (year)	Setting (N)	Grade	Intervention	Outcomes	
				Patient	Program/System
<p>Goodwin, Satish, Anderson, Nattinger, & Freeman (2003)</p> <p>Jennings-Sanders & Anderson (2003)</p> <p>[companion studies]</p>	<p>Southeast Texas, USA</p> <p>RCT component (N=335 Patients)</p> <p>Qualitative component (N=106 Patients)</p> <p>Cancer Type: Breast</p> <p>Illness stage: Newly diagnosed</p>	Ic	<p>Community based nurse case manager role: educator, counselor, advocate, and coordinator of care for the patient (home visits, telephone calls, being present with the client at physician appointments, hospital visits, etc.).</p>	<p>RCT – <u>Sources</u>: Structured questionnaire and observation of patients at baseline, 1 month, 3 months, 6 months, and 12 months, measuring type and use of cancer-specific therapies, patient satisfaction (5 items), and physical functioning.</p> <p>Use of cancer-specific therapies received in the first 6 months after diagnosis: Significantly more women in the intervention group saw a radiation oncologist. Significantly more women in the intervention group received breast-conserving surgery and radiation therapy. Of women undergoing breast-conserving surgery, greater percentages in the intervention group received adjuvant radiation.</p> <p>Arm function on the affected side: Two months after surgery, higher percentages of women in the intervention group had normal arm function and were more likely to state that they had a real choice in their treatment compared to the control group. Between groups there was no difference in patient perceptions of adequacy of information or receipt of treatment deemed appropriate by the researchers.</p> <p>Women with indicators of poor social support (e.g., living alone, unmarried, etc.) were more likely to benefit from nurse case management, i.e., differences seen in receipt of treatments deemed ‘appropriate’ depending on level of social support were diminished or eliminated in the intervention group.</p> <p>Qualitative – <u>Sources</u>: Semi-structured interview one year after cancer diagnosis, asking:</p> <ol style="list-style-type: none"> 1) What did the nurse case manager do that you felt was helpful? 2) In what ways did the nurse case manager help your family and friends? 3) What should nurse case managers do to best meet the needs of women with breast cancer? <p>Service helpful to patient themes: Managing co-existing problems, support, education, ADL assistance, and navigating health system.</p> <p>Helpful to family themes: Advocacy, support, education, and monitoring progress of loved one.</p> <p>What should nurse case managers do to best meet needs: Emotional support, other support (e.g., information), and education.</p>	<p>RCT – <u>Sources</u>: Admin data.</p> <p>Average number of patient contacts with nurse in intervention group varied from around 6.5 in first month to between one and two/month beyond the fourth month.</p>

Table 2: Quasi-experimental (two group comparisons)

Author (year)	Setting (N)	Grade	Intervention	Outcomes
				<p>Patient</p> <p>Program/System</p>
Addington-Hall & Altmann (2000)	<p>U.K. (N=2062 Patient informants)</p> <p>Cancer Type: Various</p> <p>Illness stage: End stage</p>	IIIc	<p>Macmillan nurse model or other community specialist palliative care nurse.</p>	<p><u>Sources:</u> Semi-structured interview with 'best informant' following patient's death (median time after patient's death was 10 months) asked about socio-demographics, symptoms, dependency levels, use of services (health and social care), relevant unmet needs, respondent's satisfaction with services, in the last year of life.</p> <p>Factors significantly associated with receiving the intervention were: being dependent with dressing/undressing, needing help at night, having constipation, experiencing vomiting/nausea, being mentally confused, and being under the age of 75 years. Patients receiving the intervention were more likely to live with an informal carer and less likely to live alone or in a nursing home compared to the standard care group. More patients with breast cancer, less brain and lymphoma patients tended to have received the intervention. The intervention group tended to have had higher symptom prevalence and to be more dependent in self-care tasks (e.g., bathing, dressing, toilet). No significant differences in distress among those with symptoms between groups. Patients receiving the intervention were significantly more likely to be reported as dependent in self-care tasks than patients in the standard care group.</p>
Smeenk, de Witte, Nooyen, & Crebolder (2000)	<p>Eindhoven and surrounding urban areas, Netherlands (N=116 Patients)</p> <p>Cancer Type: 31% lung, 28% intestine, 12% breast, 29% other</p> <p>Illness stage: End (less than 6 months to live)</p>	IIc	<p>Community based nurse specialist coordinator to assess patient need and coordinate care needed in home, coupled with a phone consultation service available for members of the primary care team.</p>	<p><u>Sources:</u> Patient and carers' structured questionnaires at one week before intervention (T1), one week after intervention (T2), four weeks after (T3), and three months after death (T4). Professional caregivers also received a structured questionnaire one week after patient's death. Measured 1) <i>Coordination of Care</i>: Agreement on care tasks among professional caregivers (i.e. specialist–specialist nurse coordinator, specialist–hospital nurse, specialist–GP, hospital nurse–specialist nurse coordinator, hospital nurse–community nurse, GP–specialist nurse coordinator, GP–community nurse, and community nurse–specialist nurse coordinator), 2) <i>Continuity of Care</i>: Quality of communication between patient and professional caregivers (i.e., time lapse between discharge and initial professional caregiver visit; patients asked about professional caregiver contact; carers asked same after death; professional caregivers asked about which carers they had contact with), 3) Professional care givers and patients' satisfaction with care.</p> <p>Patient survival time did not differ between intervention and control groups. Coordination of Care: Agreement poor overall with no significant differences found between groups except between 1) hospital and community nurse couples and 2) specialist and specialists nurse couples, with higher agreement in intervention group. Continuity of Care: 65% of intervention group/71% of control group were visited within two days by GP, 72% of intervention group/64% of control group visited by community nurse. Intervention group reported less contact with specialist, hospital nurse and GP, more with community nurse and home helper compared to control group. Satisfaction generally high with no significant difference between groups.</p>

Table 3: *Quantitative studies*

Author (year)	Setting (N)	Grade	Intervention	Patient	Outcomes	Program/System
Skilbeck, Corner, Bath, Beech, & Clark (2002)	Trent and Themes Regions, U.K. (N= 814 Patients, See outcomes for other N)	IVc	Macmillan nurse model	<p><u>Sources:</u> Admin data; Case records.</p> <p>Mean patient age: 68 years. Mean number of referrals to each Macmillan nurse per week: 2.8 patients. Referral source: Hospital nurse (32%), hospital MD (28%), GPs or district nurses (13%), self or family (3%). Referral reason: Patient emotional care (57%), carer emotional care (57%), symptom control (33%), pain control (27%), discharge planning (18%), information (12%). Patient death: First week of intervention (14%), within six weeks (40%), within 200 days (67%). Median number of nurse contacts per patient: With patient (2), with carers (2), with HCPs (2). Type of contact (% of patients): telephoned patient (18%), patient received home visit (89%), telephoned carer (22%), carer received home visit (7%), telephoned HCP (50%), meeting with HCP (31%).</p> <p><u>Sources:</u> Self-reporting by Macmillan nurses (N = 44) of their direct and indirect service activities, case records.</p> <p>Most common interventions on first visit: emotional care (48%), intervention for physical symptoms (34%), advice or information (32%), pain control (28%), emotional care for carer (18%). Reasons for referral: emotional care (57%), physical symptoms (33%), pain control (27%), emotional care for carer (20%), advice or information (12%).</p> <p><u>Sources:</u> ‡Patient completed (N = 76) European Organisation for Research and Treatment of Cancer Quality of Life Scale (EORTC-C30), Palliative Care Outcomes Scale (POS), and Structured Interview at 3 (not for EORTC), 7, and 28 days following referral to Macmillan.</p> <p>EORTC: No significant difference overall overtime; significant improvement found between baseline and day 7 in emotional and cognitive functioning, decline in physical functioning found between baseline and 28 days in intervention group.</p> <p>POS: Significant decline in family anxiety, and patients anxiety about their illness/treatment.</p> <p>Interview: 55% of total cases had overall positive outcome, 30% equivocal, and 7% a negative outcome. Six themes relating to how nurses benefited patients were identified – Positive Outcomes: 1) A supportive approach to care. 2) Providing information and acting as an intermediary with doctors. 3) Providing support for families and carers. 4) Leading symptom management. 5) Providing information, advice and emotional support. 6) Managing complex cases. Negative Outcomes: 1) Macmillan was a metaphor for imminent death. 2) Involvement of too many health professionals. 3) Perceived reluctance on the part of the Macmillan nurse to spend time with the patient. 4) Gaps in service provision, such as out of office hours and on weekends.</p>	<p><u>Sources:</u> Semi-structure interviews with Macmillan nurses (N = 44) and health professionals and managers, i.e., stakeholders (N = 47)/Interviews with finance professionals (N = 12)/Financial statements.</p> <p>Variation in service cost per hour found among teams (£15 to £50). Variation existed in team structure (5 of the 12 service teams had a designated team leader [in the larger teams] who liaised with higher management) and work resources available to each team.</p> <p>Work organization: Flexibility was a cherished value, especially in lieu of changing demands of clinical duties; perception that a heavy caseload effectively drives the way that Macmillan works; both formal and informal referral patterns; services that are achieving appropriate and timely referrals tend to have close links with outpatient clinics and are involved in comprehensive programs of education that include palliative care; accuracy of referral information received by Macmillan nurses and knowledge of referring HCPs was perceived as lacking, lack of familiarity of Macmillan role among HCPs.</p> <p>Conflict and ambiguity in Macmillan nurse role: Many nurses stated that formal support and supervision needed was lacking; some differences in expectations found between nurses and managers leading to role ambiguity, i.e., role expectations at odds with the day to day demands of job in terms of indirect care vs. direct care; nurses lacked resources with which to develop HCP education and consultative role.</p> <p><u>Sources:</u> Self-reporting by Macmillan nurses (N = 44) of their direct and indirect service activities, case records. Semi-structure interviews with Macmillan nurses on role management.</p> <p>Nursing activities: Direct patient care (57%); indirect activities (43%) including consultancy (8%), research (4%), staff education (11%), staff emotional support (4%), policy development (6%), other (11%).</p>	
Clark, Seymour, Douglas, Bath, & Bech (2002)	<i>Cancer Type: Various</i>					
Seymour, Clark, Hughes, Bath, & Beech (2002)	Illness stage: 67% palliative, 6% curative, 19% newly diagnosed, 9% newly diagnosed and palliative					
Skilbeck & Seymour (2002)	‡ Patient subgroup (4% palliative, 13% curative, 17% newly diagnosed, 67% newly diagnosed and palliative)					
Corner, Halliday, Havil, Douglas, & Bath (2003)						
[companion studies]						

Table 3 cont.: Quantitative studies

Author (year)	Setting (N)	Grade	Intervention	Outcomes	
				Patient	Program/System
Evans & Kelly (1995)	U.K. (N=48 Patients) Cancer Type: Not indicated Illness stage: 54% undergoing treatment, 38% completed treatment, 8% palliative	IVd	Macmillan paediatric nursing	<p><u>Sources:</u> Patient mail survey about sources of support and satisfaction.</p> <p>Macmillan may have facilitated treatment related activities in home. 91% stated service had increased confidence about sending child back to school. 76% stated that number of Macmillan visits were appropriate, 13% said not enough.</p> <p>Types of care given: advice on care (95%), reassurance (81%), disease information (86%), nursing tasks (57%), and delivering supplies (49%).</p>	<p>First meeting with Macmillan nurse, same day of diagnosis (11%), during 1st week in hospital (41%), before discharge (27%), after discharge (14%).</p> <p>After discharge, contacts named as a source of advice were oncology wards (81%), Macmillan Peds. nurses (57%), and GPs (38%).</p>
Douglass & Venn (1999)	U.K. (N= 60 Patients; 34 Carers; 4 Macmillan nurses; 52 District Nurses [DN]; 168 GPs) <i>Cancer Type: Not indicated</i> Illness stage: Various	IVd	Macmillan nurse model	<p><u>Sources:</u> Structured questionnaires: Asked patients and carers about referral, main problems helped with, what was done best, and what could have been done better; asked GPS and DNs about referral and perceived quality of service.</p> <p>Patients and carers: 96% of patients and carers felt that referrals were appropriate and 90% felt they were timely. Findings suggest that Oncs and GPs need to refer their patients sooner to Macmillan. Patients and carers were aware of the particular role Macmillan nurses play. Emotional support followed by information giving, were identified as the most frequent forms of assistance. Most patients stated that there was nothing more that the Macmillan nurse could have done for them. Majority of patients and carers felt that time Macmillan spent with them was "just right". Rated satisfaction with service = 9.2/10 overall.</p> <p>HCPs: Majority of Macmillan nurses, GPs, and DNs felt that referrals were timely. GPs and DNs felt that Macmillan nurses differed from other services in advice and counselling they provide. 93% of GPs and 83% of DNs said that the Macmillan nurses enable them to provide more effective care. 80% of Macmillan nurses responded that they had met patients' needs, 60% that they had met carers' needs. 46% of Macmillan nurses stated that there were limitations in the service that they were able to provided, namely due to limitations: a) imposed by patient or carer, b) in nursing resources, c) imposed by other organizations, d) as result of patient illness.</p>	See patient outcomes.

Table 3 cont.: *Quantitative non-comparative studies*

Author (year)	Setting (N)	Grade	Intervention	Patient	Outcomes	Program/System
Sloan & Grant (1989)	U.K. (N=45 Carers; 183 GPs; 70 District Nurses; 14 Ward sisters) Cancer Type/ Illness stage: Not indicated	IVd	Macmillan nurse model	See program/system outcomes.	<p><u>Sources:</u> Structured questionnaire. How helpful are the Macmillan nurses in terms of:</p> <ol style="list-style-type: none"> 1) someone to talk about cancer care, 2) link with health services, 3) advice in medicine? <p>In talking about cancer, 90% of all groups though Macmillan very helpful. In providing medicine info, 84% of carers and district nurses thought Macmillan very helpful, GPs thought Macmillan fairly helpful. Timing of referral - 78% of carers said "just right", 22% "late". As a link to health services, 80% of carers thought very helpful, GPs had concerns about being able to contact and coordinate with Macmillan nurses. Macmillan integral part of primary health care team: GP = 36%/District Nurses = 40%. Macmillan useful addition to community services: GP = 58%/District Nurses = 58%. Macmillan duplicates district nursing services: GP = 6%/District Nurses = 2%. No need for Macmillan nursing services: GP = 0%/District Nurses = 0%.</p>	
White, Given, & Devoss (1996)	Michigan, USA (N=133 Patients) Cancer Type: 17% lung, 13% colon, 36% breast, 8% prostate, 26% other Illness stage: Various	IVd	Clinic based APN role: 1) Educate patient and improve access to information. 2) Provide symptom management. 3) Develop and/or link to community resources. 4) To serve as care managers.	<p><u>Sources:</u> Admin data – computerized patient record following patients for duration of intervention, typically six to eight months.</p> <p><i>On assessment: 78% of patients in program had a knowledge deficit, this being greatest in the area of basic knowledge of the disease process, followed by that related to chemotherapy.</i></p> <p>The most common nursing teaching interventions (as percent of total interventions) for the five disease sites were for:</p> <p>LUNG: Fatigue, inadequate breathing, impairment of sensory perceptions, acute pain. PROSTATE: Chronic pain, inadequate finances, sexual dysfunction. BREAST: Infection, fatigue, acute pain, inadequate health-seeking behaviours. COLON: Fatigue, chronic pain, inadequate health-seeking behaviours. OTHER: Altered health maintenance, chronic pain, altered nutrition, acute pain.</p>	None	

Table 1: Qualitative studies

Author (year)	Setting (N)	Grade	Intervention	Patient	Outcomes
Cox, Bergen, & Norman (1993)	London, U.K. (N=8 Patients, 8 Carers, 5 District nurses (DN), 2 GPs.) Cancer Type/ Illness stage: Not indicated	5	Macmillan nurse model	<p><u>Sources:</u> Semi-structured interview to identify critical incidents in care.</p> <p>Total of 11 responses (not mutually exclusive) to 9 different negative themes, e.g., Not visiting at certain times (2 DNs); Separating specialist services (2 DNs); Earlier contact needed (1 patient).</p> <p>Total of 82 responses to 12 different positive themes, e.g., 19 responses relating to specialist knowledge in area of terminal cancer care (DN, GP, patient, carer); 12 responses relating to provision of psychological care and emotional support for patients and carers (DN, patient, carer); 10 responses relating to liaison skills, working together and knowledge of available services (All); 10 responses relating to having time to talk and listen to patients (DN, patient); 6 responses relating to providing continuing care (patient carer); 5 responses relating to being available and easy to contact (patient); 5 responses relating to providing carer support (carer); 4 responses relating to providing an informal friendly service (patient).</p>	<p>Program/System</p> <p>See patient outcomes.</p>
Raynes, Leach, Rawlings, & Bryson (2000)	West Yorkshire, UK (N=27 Patients) Cancer Type: Various Illness stage: End stage	2	Macmillan nurse model	<p><u>Sources:</u> Three focus groups asked:</p> <ol style="list-style-type: none"> 1) What kind of help are you currently receiving? 2) What additional help do you want? 3) What is the most important of the help that you are receiving? <p>Patients reported receiving a wide range of services. In addition to specialist nursing services; all groups agreed that they were receiving cleaners services and specific state benefits.</p> <p>Patients wanted more help getting out, with housework, and with support from Macmillan nurses.</p> <p>Most of what patients wanted was practical help that affected daily living.</p>	None

Table 1 cont.: *Qualitative studies*

Author (year)	Setting (N)	Grade	Intervention	Patient	Outcomes
Howell, Fitch, & Caldwell (2002)	Toronto, Canada (N=20 Patients) Cancer Type: Various Illness stage: 30% end stage, 70% recurrent	5	<i>Interlink</i>	<p><u>Sources:</u> Semi-structured interview in which patients were asked about <i>Interlink</i> experiences (phenomenological approach), i.e., data gathering statements: 1) How did <i>Interlink</i> affect you? 2) Experiences with <i>Interlink</i>? 3) What happened with <i>Interlink</i> and how did you feel about it?"</p> <p><i>Impact of Interlink viewed as positive by patients:</i></p> <ul style="list-style-type: none"> a) someone to share the cancer journey, b) opportunity for emotional unburdening, c) addressing all needs, d) helping to understand illness, e) providing a link to information and resources, f) stabilizing force, g) helping to uncover the strength to survive. 	None

Appendix B

Table 1: Referrals for Interlink to other service providers

<u>Organization</u>	<u>Referrals</u>	<u>Organization</u>	<u>Referrals</u>
CCAC	80	VON-RN	2
HOSPICE	27	AIRLINE	1
RN	26	CANCER CONNECTION	1
COMMUNITY SERVICES	20	CASEY HOUSE	1
HCC	20	CIRCLE OF CARE	1
PALL CARE PHYSICIAN	15	COOPS	1
TEMMY LATNER	12	DIABETIC EDUCATOR	1
MD	11	DIETICIAN	1
GP	10	EMERGENCY	1
FAMILY	9	HAZEL BURN HOSPICE	1
SW	9	HOSPITAL -DOCTOR	1
YEE HONG	9	HOSPITAL-SW	1
HPC NET	8	HOSP-SW	1
BAYCREST	7	HOUSING	1
DR	7	HUMBER COMMUNITY	1
FAMILY DR	7	JEWISH HOSPICE	1
HCN	7	KCI	1
CCS	6	LIFE LINE	1
PALL CARE UNIT	5	MEALS ON WHEELS	1
HOSP-RN	4	ONTARIO WORKS	1
PALIN	4	PALL CARE COORD	1
RED CROSS	4	PALL CARE NURSE	1
SCARB HOSPICE	4	PMH-PSYCHOLOGICAL	
AMBULANCE	3	DEPT	1
ONCOLOGIST	3	RADIATION ONCOLOGIST	1
PHARMACIST	3	SCARB CC	1
PMH	3	SEHC-CHAPLAIN	1
PMH-RN	3	SGH-RN	1
BEREAVEMENT		SMH	1
COUNSELLOR	2	SOCIAL SERVICES	1
CCEY	2	SPRING	1
CHAPLAIN	2	ST. CLAIR WEST	1
CNH	2	SURGEON	1
HBH	2	T.T. NETWORK	1
HOMEMAKER	2	TORONTO GRACE	1
LAWYER	2	VET AFFAIRS	1
PALL PHYSICIAN	2	VOLUNTEER	1
PMH-SW	2	VON	1
SEHC-RN	2	WELLSPRING	1
TRINITY HOSPICE	2	Not specified	75
TT NETWORK	2	TOTAL	466
TT PRACT	2		

Table 2: *Professions of service partner respondents (n = 26).*

<u>Profession</u>	<u>Number</u>
CCAC case manager	7
Physician	5
Social worker	5
Nurse (Institutional)	4
Nurse (community)	3
Program coordinator	2
TOTAL	26