

# Making cancer bearable: The Interlink Community Cancer Nurses model of supportive care

By Doris Howell and Jean Jackson

## Abstract

*Most cancer patients and their families experience the full impact of their diagnosis and the disruptions cancer brings to their lives in their own homes and communities. Access to supportive care programs within the community is critical if we are to assist these individuals in coping and adjusting to the realities of cancer.*

*Interlink Community Cancer Nurses, a nonprofit nursing agency, provides supportive care across the continuum of cancer care from early diagnosis and treatment through to remission and/or palliative care through its independent model of supportive care delivered by expert oncology nurses. The program utilizes a unique, client-centred model of care delivery to ensure that needs are met, and to link patients to community services which promote their ability to meet the demands of cancer.*

*Interlink's program of supportive care demonstrates that oncology nurses can make a significant impact on the outcomes of cancer for individuals and their families which may impact on cost, influence survival and enhance quality of life.*

## Introduction

Cancer remains a devastating disease which disrupts every aspect of life for the individual and family, often creating feelings of dread and despair. Many of these individuals and their families will need assistance in coping and adapting to the physical, psychological, social, spiritual, and financial realities of cancer as they move along the continuum of illness. As a result of early

discharge, complex treatment regimens and an increasing emphasis on ambulatory care, most of the realities of cancer will be faced by the patient and family in their own homes and communities. People living with cancer in the community may have had little time to absorb the impact of diagnosis, and to understand the self-care management strategies needed to deal with cancer and treatment. Subsequently, they may experience more intense physiological and emotional needs and require supportive care within the community. Access to community based supportive care is critical if we are to influence the ability of the individual and family to adjust and adapt to cancer.

## Supportive care

Supportive care embraces the full range of issues that emerge for an individual as the impact of the illness and treatment are felt and the person tries to manage the experience (Fitch, 1994). Supportive care is necessary to help that individual deal with the uncertainty of cancer, manage the impact of cancer and treatment, augment their own abilities in dealing with the day-to-day adjustments required in coping with cancer, and preserve or maintain quality of life. Supportive care for persons living with cancer is defined as:

*... the provision of the necessary services as defined by those living with or affected by cancer to meet their physical, informational, emotional, psychological, social and spiritual needs during the pre-diagnostic, diagnostic, treatment and follow-up phases, encompassing issues of survivorship, palliation and bereavement" (Ontario Cancer Treatment and Research Foundation, 1994).*

## ABRÉGÉ

### RENDRE LE CANCER TOLÉRABLE: LE MODÈLE DE SOINS DE SOUTIEN DES INFIRMIÈRES EN ONCOLOGIE D'INTERLINK OEUVRANT EN SANTÉ COMMUNAUTAIRE

C'est à leur domicile et dans leur collectivité que la plupart des patients atteints de cancer et leurs proches vivent l'impact global de leur diagnostic et les perturbations que la maladie entraîne dans leur vie. Il est crucial que ces personnes aient accès à des programmes de soins de soutien dans leur localité si on veut les aider à s'adapter aux réalités du cancer et à y faire face.

Les infirmières en oncologie d'Interlink, un organisme de soins infirmiers à but non lucratif, prodiguent au sein de la communauté des soins de soutien tout au long de la trajectoire de la maladie, du diagnostic précoce au traitement, en passant par la rémission et/ou les soins palliatifs; ces infirmières spécialisées en oncologie dispensent les soins de soutien en vertu d'un modèle spécifique mis au point par cet organisme. Le programme est basé sur un modèle de prestation de soins unique en son genre axé sur les patients. On s'assure ainsi que les besoins des patients sont satisfaits et on les oriente vers les services communautaires qui favorisent leur capacité de faire face aux exigences de la maladie.

Le programme de soins de soutien d'Interlink montre que les infirmières en oncologie exercent une influence significative sur l'issue du cancer chez les patients et leur entourage et que cette influence pourrait avoir un impact sur les coûts et améliorer la survie ainsi que la qualité de vie.



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## Magnitude of need

Recent statistics indicate that one in three Canadians will develop cancer during his lifetime (National Cancer Institute of Canada (NCIC), 1997). A survey of needs of cancer patients revealed that the psychosocial and instrumental needs of many cancer patients and their families are not being met (Cancer 2000 Task Force Report, 1992). Similarly, women with breast cancer reported the need for improved communication with health care professionals, and access to information and support within the community (Report on the National Forum on Breast Cancer, 1994).

## Interlink's program of supportive care

Interlink Community Cancer Nurses was developed to respond to these unmet needs and subsequently has been providing supportive care to adults within the community of Toronto for the past 10 years. At present the Interlink program is only able to provide service to adult patients in the Metro Toronto area. However, plans for expansion provincially are in the proposal stage. Paediatric Interlink nurses provide care to children and their families throughout the province of Ontario.

Interlink Community Cancer Nurses is a nonprofit, community based agency which enables adults and children with cancer and their families to access the care and support they require at all stages of illness. Interlink nurses provide specialty expertise which contributes to the clinical management of disease and treatment side-effects while providing essential psychosocial care. Interlink nurses seek to minimize the trauma experienced by a person diagnosed with cancer, promote optimal function and well-being, and improve or maintain quality of life. These client words illustrate the influence of the Interlink nurse on patient well-being:

*Interlink was able to support me in finding the resources I have needed to maintain the highest level of wellness possible while dealing with cancer treatments.*

Interlink nurses function as independent practitioners and carry a caseload of approximately 55-60 cancer patients in the community. The intensity of patient and family needs vary within the caseload. Subsequently, some patients will require frequent contact with the Interlink nurse (weekly visits) while other patients may only require monthly follow-up in order to keep them well, and to anticipate potential crises as a result of progressive disease. The care provided by the Interlink nurse is reflective of the individual's unique experience of cancer. Her effect on each patient is uniquely felt, as described by this patient:

*Interlink was very helpful in helping me to 'find my feet' in an overwhelming situation. It was great to have a calm, informed counselling voice to talk over fears and resources when I was at my lowest ebb.*

Interlink nurses provide support to patients and families as the patient moves across the illness trajectory from early diagnosis through to cure or palliation. Over the past 10 years, Interlink nurses have provided supportive care to over 14,000 individuals with cancer and their families. The extent of the involvement of Interlink nurses across the continuum is dependent upon needs and on the availability of existing support services within the community. Throughout the existence of the program the needs of patients have not changed and people with cancer in the community continue to seek the assistance of Interlink nurses to support them in adapting to the difficult experience of living with cancer. Many patients describe a sense of security and comfort knowing that a care provider with expertise in cancer is accessible to them:

*Our lives were made much better and easier at a most difficult, upsetting, painful and confusing time. This service should be given to all patients with cancer.*

## Interlink's program components

The Interlink program is modeled after the Macmillan nurse program in the United Kingdom (Bunn, 1988). Macmillan nurses are specialists who work in the community and other settings,

complementing the work of nurses and other health professionals who care for people with cancer. They offer specialist support, advice and help, depending on the needs of patients and families and the skills of the professionals involved. Similarly, the role of the Interlink nurse is one of being expert practitioner and patient advocate for patients and their families, particularly early in the diagnostic and treatment period where education, counselling and supportive care are required. Interlink nurses also provide consultation and education to primary care providers to support the delivery of effective, high quality care to cancer patients and their families in the community. The Interlink program is comprised of four essential components, namely; clinical care, education, community development and research.

## Clinical care

### Responding to the human consequences of cancer

The unique role the Interlink nurse plays in supporting an individual and/or family throughout the cancer experience and the relationship with other health professionals in the community or institutional setting is not immediately self-evident because the Interlink nurse does not provide traditional "hands-on" nursing care. What differentiates the Interlink nurse from others is her ability to bring indepth expertise in community oncology to the practical and human needs of individuals experiencing cancer from the earliest stage of diagnosis through to remission or palliative care. In working with individuals with cancer and their families, the Interlink nurse draws on her oncology/palliative expertise to focus her attention on the physical effects of the disease - the multiple fluctuating symptoms and varying levels of pain faced by people with cancer - as well as on the human consequences of cancer. Interlink nurses assist patients and families in dealing with realities such as loss of work and income, breakdown of relationships within the family, potential psychosocial crises and general chaos.

### Client-centred, empowerment model of care

The Interlink program utilizes a model of client-centred care with empowerment and partnership at the centre. The Interlink nurse empowers the patient in negotiating a complex health care system while advocating for access to services. This model of care provides the Interlink nurse with the fluidity and flexibility to meet needs as determined in partnership with the individual and family. The role of the Interlink nurse is prescribed by the patient and family's experience of cancer and might include:

- detecting and responding to complex reactions to illness that influence recovery and rehabilitation, including early referral of patients at risk for psychological morbidity
- providing expert coaching and supportive counselling to teach patients/families strategies to maximize their ability to live with cancer and cope with the uncertainty and emotional impact of cancer
- anticipatory teaching and guidance in managing the physical and psychosocial sequelae of the disease and in dealing with transitions across the trajectory of illness
- assessment of needs and mobilization of formal and informal resources to create a community of support around the individual and family to foster adaptation and family adjustment
- liaison with treatment centres to alert the health care team to factors in the home environment which influence response and impede recovery
- prevention, assessment and early intervention for high incidence problems unique to diagnosis and treatment of cancer and mobilization of medical support for the treatment of oncological emergencies
- expertise in pain and symptom management and in the appropriate titration of medications for symptom relief
- addressing instrumental needs such as day care for children, linking with services to address financial concerns

## Bridging the gap between treatment centre and home

Hospital and the home are two distinct and different worlds and often institutional caregivers are unable to understand the complexity of the issues facing patients in the community. Interlink nurses become the bridge between these two worlds, working with the patient in the community to help integrate what they have been taught in hospital and collaborating with the caregivers in hospital to assist them in understanding the world of the patient at home.

### Access to care and resources in the community

Interlink nurses work collaboratively with other health care professionals, such as visiting nurses and family physicians to ensure that needs are met. Interlink nurses do not assume the functions of the visiting nurse but work collaboratively with the visiting nurse sharing oncology nursing expertise as a consultant. The role of the Interlink nurse is dependent upon the expertise of the visiting nurse and the needs and wishes of the patient. Interlink nurses provide ongoing psychosocial support to the patient and family that complements care provided by visiting nurses.

Patients recognize the need for continued Interlink nurse involvement even when other service provider agencies are involved. In a 1996 Interlink patient survey, 94% of patients stated that the Interlink service was still needed even if other visiting nurse agencies were involved in the patient's care. Patients describe the Interlink nurses' expert knowledge and ongoing psychosocial support as a key to their survival and sense of security in facing cancer. Key differences between the primary focus of the Interlink nurse and the visiting nurse are described in Table One.

Interlink nurses link individuals to community services including home care and bring specialized knowledge of cancer to affect decision making in service provision decisions made by community care case managers. Many Interlink patients are not currently eligible for home

**Table One: Relationship between Interlink nurse and visiting nurse**

Interlink Nurse Role	Visiting Nurse Role
Management of human response to illness is primary focus while attending to clinical aspects of illness.	Management of disease symptoms, technology is primary focus while attending to psychosocial responses.
Emphasis on information, counselling and support for the individual and family.	Provision of information and psychosocial support may be limited due to time restrictions.
Independent practice organized to respond to needs as determined by patient and nurse.	Amount of nursing service and role of nurse is coordinated and determined by provincial home care program.
Able to intervene early in diagnostic and treatment period and provide support along the whole of the continuum of cancer care.	Care is episodic and dependent on eligibility for nursing services through provincial home care program.
Oncology/palliative care expertise and certification in oncology nursing is mandatory.	Oncology/palliative specialty knowledge is variable.

care services but have ongoing informational and supportive care needs. Currently only 32% of the Interlink caseload are eligible for home care services. The primary focus of the Interlink nurse is on responding to patient and family reactions along the continuum of illness. Key differences between the role of the Interlink nurse and the community service coordinator/case manager have been identified in Table Two.

### Integrating supportive care

Interlink nurses seek to integrate multiple supports for patients and families from both formal and informal sources of support in order to achieve a coordinated system of support that optimizes patient functioning and well-being. A patient describes the impact of coordination:

*The Interlink nurse linked all the services together, as most parties concerned never knew what else was set up or happening, but your service tied them all together and knew what steps to take with changes in health as time went on.*

Figure One depicts the multiple sources of support mobilized by the Interlink nurse to achieve a community of support around the patient and family.

### Referral patterns

The most frequent reasons for contacting Interlink are to obtain: a specialized assessment by an expert community oncology nurse to

**Table Two: Relationship between Interlink nurse and the home care case manager**

Interlink Nurse: Clinical Management	Home Care Case Manager: Service Manager
Expert knowledge and expertise in cancer care to assess needs and provide interventions.	Generic knowledge of wide range of illness and support services to address needs.
Contributes clinical knowledge to decision-making assessment of need for services and advocates for services.	Utilizes extensive knowledge of community resources for patient referral.
Uses clinical expertise to assess appropriate formal and informal sources of support and links patient to both, ensuring a network of support around patient and family.	Assesses eligibility for services from contracted community agencies.
Early intervention and involvement at time of initial diagnosis and treatment.	Coordinates and authorizes provision of eligible home care services by contracted community agencies.
Provides coaching to patient and family in utilizing support to enhance strengths.	Case coordination to broker services to patient who meets eligibility criteria in the home.
Assessment and interventions for human response to illness.	Patient is the focus of assessment and coordination of service within resource limitations.
Detects complex biopsychosocial and spiritual responses to illness.	Authorizes provision of primarily technical and physical needs services by generalist nurse and other care providers.
Continuous involvement with patient/family along continuum of illness.	Episodic involvement with patient.

determine unmet needs; to provide guidance to patients and families in facing the demands of progressive illness; to link patients with appropriate community services as circumstances change; to ensure the provision of information, education and psychosocial support; and to access expertise in pain and symptom management. Following initial contact, the Interlink nurse establishes telephone contact, usually within 24 hours, depending upon patient and family need, to plan a home visit.

Referrals to the program come from multiple sources such as visiting nurses, ambulatory treatment centre nurses, social workers, volunteers, patients and their families who are struggling at home to meet the demands of a cancer diagnosis. Referral sources for a two-year period are depicted in Table Three. Many of these patients described how they wish they had known about the service sooner, as they would not have found their experience with cancer so difficult:

*"Interlink should have a place in the cancer wing of hospitals to advise patients about the illness. I wish we had the service sooner", "This service should be given to all patients with cancer."*

*"We need this emotional help and support and comfort in dealing with this illness."*

### Interlink's patient population

Many of the patients referred to the Interlink program do not require ongoing assistance and support. About 25% of patients referred to Interlink react to the initial diagnosis as a crisis but, with mobilization of resources, information and supportive counselling by the Interlink nurse are able to function and manage. The following patient describes her initial need for the Interlink nurse:

*The Interlink nurse managed to keep me in one piece at a critical time.*

Interlink nurses provide oncology nurse specialist care to three populations of patients:

- those who require minimal intervention but need initial assistance in dealing with the uncertainty and trauma of a cancer diagnosis and who seek assistance to understand cancer and the resources available to them

- those requiring ongoing management of cancer and its treatment, whose ability to manage is made possible by the Interlink nurses' ongoing and continual mobilization of resources
- those who need ongoing support to maintain stability and prevent crises, either because of an advanced cancer diagnosis or because of vulnerability.

### Supportive care to vulnerable populations

Vulnerable patients with cancer and their families comprise the ongoing caseload of the Interlink nurse. A recent analysis of the Interlink nurses' caseload revealed that at least 40% of the caseload was comprised of complex patients. The elements comprising this complex patient population were identified as follows:

- chaos as an initial and ongoing response to cancer
- family turmoil (eg. Hx of abuse, alcoholism)
- frail elderly patients (ie. co-existing illness, living alone, minimal/absent support)
- young families with small children
- minimal or absent support
- lack of financial resources, poor socioeconomic status
- anger and/or denial as primary emotional response to illness
- more than one primary diagnosis of cancer
- previous history of cancer in family members
- frequent need to mobilize resources to prevent psychological crises
- pre-existing psychiatric disorders
- complex symptom management issues

This population of patients/families requires intense involvement of Interlink nurses, who are frequently mobilizing resources to avert crises in this group. Similar indicators of vulnerability have been described in the literature as indicators of poor psychosocial adjustment to cancer (Rowland, 1990).

### Care of the child:

#### Interlink's paediatric program

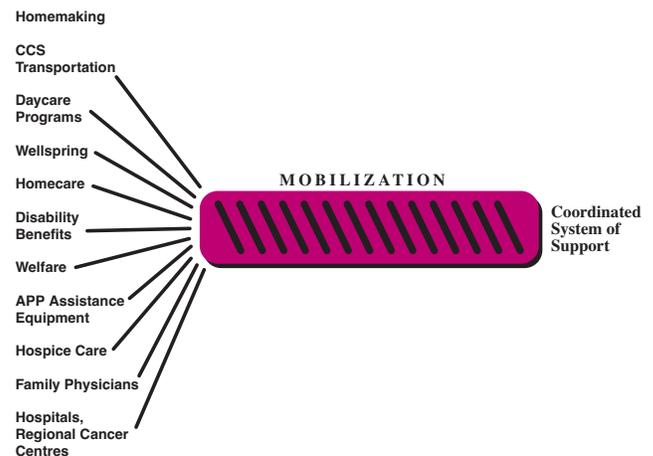
The task of caring for children at home can be very difficult without specialist support (Bennett, 1984). Paediatric Interlink nurses provide a vital link between the cancer treatment centre and the community in five regional treatment centres across Ontario with plans to expand the program nationally in a partnership with Candelights Canada.

The paediatric Interlink nurse is stationed within the treatment centre and usually meets the child and family as soon as possible after the diagnosis of childhood cancer and prior to discharge. Parents of children with cancer require a link with the treatment centre and someone to facilitate the difficult transition from hospital to home (Forsyth, 1992).

**Table Three: Referral source, 1995 - 1996**

	#	%
<b>Hospitals</b>		
Social workers	161	
Registered nurses	45	
Discharge planners/HCCs	8	
Oncologists/physicians	10	
	224	36.8
<b>Home care (HC)</b>		
Coordinators	44	
RNs - VON	10	
RNs - St. Elizabeth	10	
	64	10.5
<b>Other health care providers</b>		
RNs - other than hosp or HC	54	
Family physicians	13	
	67	11.0
<b>Other sources</b>		
Self/family/friend	200	
Canadian Cancer Society	45	
Other	9	
	254	41.7
<b>Total Admissions</b>	<b>609</b>	<b>100</b>

**Figure One: Coordinated, integrated care**



Together with the family, the nurse assesses the family supports and identifies their unique needs in meeting the child's needs within the community. As the parents deal with the shock of diagnosis, the Interlink nurse is already beginning to help. Over the following few weeks or months, the Interlink nurse assists the family in sorting through the maze of services and resources they require. Paediatric Interlink nurses support the care of children with cancer in the community by:

- providing information to the family to help them understand the complexities of cancer treatment protocols and the demands it will make upon the family
- visiting the child's school to prepare teachers and classmates in understanding the illness and ways of being supportive to the sick child
- arranging for financial assistance for families who will experience a significant financial strain as a result of treatment and loss of income during the child's cancer experience
- providing ongoing psychosocial support for families, particularly counselling families on sibling support and frequently providing direct emotional support to siblings
- coordinating resources and advocating for families to ensure they receive the assistance required
- providing consultation to other care givers for children who require palliative care and supporting child and family in dealing with terminal illness

## Education program

Interlink nurses provide education to other health care professionals through consultation, preceptorship programs, exchange programs, presentations at conferences, lectures at universities/colleges and through the development of comprehensive nursing guides to specific solid tumour cancers, such as ovarian cancer. Interlink is the only independent, community nursing program comprised of nurses whose sole area of expertise is oncology. Interlink is a model program for demonstrating and educating other nurses in independent, oncology nursing care delivery within a community. The ongoing development

of the Interlink nurse is supported through weekly educational sessions and monthly peer reviewed reflective practice sessions.

## Community development

Interlink nurses work within each of their communities to advocate for the development of programs and resources for the person with cancer and his family. In a one-year period Interlink nurses participated in over 15 community, provincial and federal policy and planning committees to advocate for the needs of people with cancer and their families in order to influence the direction of communities in setting policy about service provision for people with cancer.

## Research

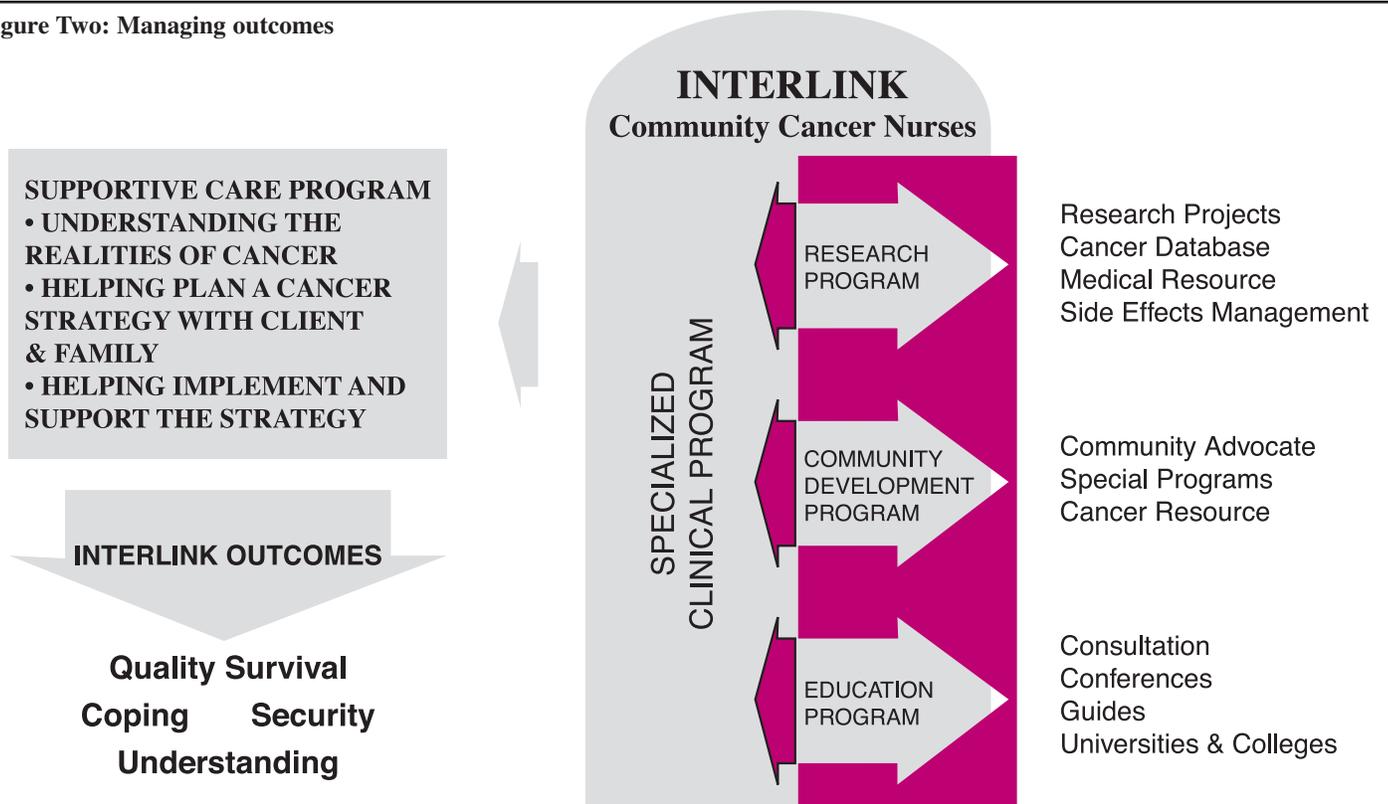
Interlink has maintained a comprehensive client and service information database over the past 10 years. It provides information on Interlink's patient population and is used for research and strategic planning. Plans are currently underway to develop an effective system to measure intensity of patient need and specialist nursing support requirements in a community population.

It is critically important to demonstrate that the support provided by Interlink nurses makes a difference to patient care. A qualitative study is currently being conducted to determine the impact of the Interlink nurse on the meaning of living with cancer in the community. Results of this study will be available in the fall of 1998. Further research priorities will emphasize therapeutic outcomes of specialist nursing practice in managing symptoms such as breathlessness.

## Interlink makes a difference to people with cancer

*I can't imagine what a nightmare it would have been for us without Interlink in our lives during the last months of my husband's life.*

Figure Two: Managing outcomes



Cancer remains a devastating disease. Patients struggle to make sense of what is happening to them and to meet the demands of treatment, making small and massive adjustments to their everyday lives in the face of the disruption the disease brings (Corner, 1996). As more emphasis is placed on the treatment and cure of cancer we must not forget the impact of the illness on the day-to-day lives of people with cancer. Oncology nurses play a significant part in facilitating the process of recovery from cancer. Jessica Corner (1996) describes the care provided by oncology nurses as a therapeutic enterprise in its own right. She asserts that it is expert oncology nursing care that will be able to reconstruct the language of cancer care to move it beyond the mere biomedical aspects of cancer treatment to become responsive to the human experience of cancer. The Interlink program is demonstrating the nurse's ability to provide care that is responsive to the biomedical and psychosocial needs of the patient and family. The care provided by the Interlink nurse is contributing to positive patient outcomes and may be impacting on the cost of care.

## Managing outcomes

Interlink nurses contribute to the effective coping of individuals with cancer and their families, positively affecting patient outcomes by facilitating individual and family coping and enabling them to manage the disease and its treatment. Figure Two depicts the devastating impact of cancer on patients and their families without effective support and the potential impact of the Interlink nurse role in achieving positive patient outcomes through the clinical management of the illness trajectory. Effective supportive care provided by specialist oncology nurses may have an impact on the quality of a patient's survival and significantly influence the cost of care.

Research demonstrating the effectiveness of specialist cancer nursing on patient outcomes is sparse. However, a few studies have demonstrated the effect of supportive care on patient outcomes and these are described in the following sections. Thus, it can be postulated that the supportive care role of the Interlink nurse may contribute to significant outcomes such as a reduction in health care costs, improved psychosocial adjustment and coping, lessening of the burden of cancer, improved well-being and survival, enhanced self-care and recovery, and ultimately quality of life.

### Reduction in health care costs

Specialist community oncology nurses can potentially influence the cost of health care through reducing hospital admissions and addressing problems before they become acute and more expensive to treat. Patients with lung cancer who received specialist oncology nursing visits at home had fewer hospital admissions for symptoms and complications associated with malignancies (McCorkle, 1989). A retrospective analysis of Interlink data indicated that 16 hours (\$565) of targeted specialist intervention provided to just one patient over a two-month period by the Interlink nurse potentially averted this patient's admission to a palliative care unit for the final three weeks of life at a cost of \$550/day, a total cost of \$11,550 to the health care system. A reduction in length of stay has also been noted for patients who received early assessment and referral for supportive care services, coordinated self-care education and home visits for monitoring and evaluation of care, and the provision of emotional support and counselling within a specialist community nursing HMO (Ethridge, 1991).

Supportive counselling and care that contributes to effective coping and adjustment have been linked to a reduction in health care costs. Poor adjustment to illness has been found to be a leading individual characteristic linked to high use of all types of services (Browne, 1995) and patients with poor adjustment and ineffective coping may use health care resources as a type of health-seeking behaviour (Browne, Arpin, Corey, Fitch, Gafni, 1990).

### Improved psychosocial adjustment and coping

The provision of educational counselling and emotional support to patients early in the course of their diagnosis and treatment may

influence adjustment and adaptation. A lack of information has been found to contribute to the manifestation of psychological problems (Steptoe, Sutcliffe, Allen, Coombes, 1991). Specialist nurse counselling has been found to reduce psychiatric morbidity (Maguire, Pentol, Allen, Tait, Brooke, Sellwood, 1982), contribute to faster adjustment in cancer patients (McCardle, George, McArdle, Smith, Moodie, Hughson, Murray, 1996), and prevent the development of psychological morbidity later (Nash, 1995). Perceived level of emotional support was associated with a better adjustment outcome in breast cancer patients (Irvine, Brown, Crooks, Roberts, Browne, 1991) and has been found to be predictive of psychological adjustment (Funch, Mettlin, 1982).

### Improved well-being and survival

The provision of psychosocial support by the Interlink nurse contributes to patient adjustment and coping which may have prognostic significance. Improved survival has been linked to the provision of psychosocial support (Greer, Watson, 1987; Spiegel, 1989; Nishimoto, Mediansky, Mantell, 1992). Maunsell, Brisson, Deschenes (1995) found that support provided in the first three months after a diagnosis of breast cancer was associated with improved survival. Interlink patients, during a recently conducted qualitative study, described the Interlink nurse as essential for their survival and their care as being life-extending (preliminary analysis, full study to be published at a later date). Patients who received home visiting in combination with counselling lived longer than did control patients (Richardson, Shelton, Krailo, Levine, 1990) and had lower rates of recurrence (Fawzy, Fawzy, Hyon, Elashoff, Guthrie, Fahey, Morton, 1993). Fewer deaths were noted in a population of patients assisted by nurses in the community to resolve their health problems with advice, support and education (Heslop, Bagnall, 1988).

### Enhanced self-care and recovery

The use of an enabling and empowering model of care delivery by the Interlink nurse may contribute to enhanced self-care which may have a positive outcome for patients. Patients who are empowered are able to manage their own health care more effectively (Wuest, 1991), and patient education generates greater accountability for self-care among patients (Crawley, Till, 1995). The ramifications for surviving the cancer experience extend far beyond the medical diagnosis and treatment. Other factors affecting recovery are psychological, social, economical, vocational, legal and spiritual in nature. Interlink nurses seek to ensure the supportive care needs of patients and families are met across the continuum of cancer care.

### Lessening of the burden of cancer

Through the provision of clinical management of the illness and early anticipation of side effects, Interlink nurses may be helping to reduce the burden of cancer for patients and their families. Fewer hospital admissions for symptom distress and complications associated with cancer were noted in patients with lung cancer who received specialist oncology nurse visits at home (McCorkle, Benoliel, Donaldson, Georgiadon, Moinspour, Godell, 1989). Nurse specialists in a pain service resulted in statistically significant changes in reported levels of pain and analgesic prescribing patterns (Mackintosh, Bowles, 1997). Increased availability of specialist palliative nursing in the community helps to ensure that more patients receive specialist palliative care (Nash, 1992).

The family support provided by the Interlink nurse may lessen caregiver stress. The psychological and physical status of the patient reverberates throughout the entire family with resultant distress in family members of depression, anxiety and grief (Kissane, Block, Burns, McKenzie, Posterno, 1994). Unmet needs of patients were often linked to caregivers overwhelmed by the demands of caring for the patient (Seigel, Raveis, Houts, Mor, 1991). Coordinated support in the palliative phase of illness has the potential to reduce the rate of hospitalization of cancer patients (Wodinsky, 1992). More importantly, effective relief of symptoms in palliative care may lessen the patient's cry for euthanasia (Lamerton, 1992).

## Improved quality of life

Knowledge and caregiver experience in cancer care may contribute to an enhanced quality of life through the provision of appropriate guidance, education and support. Padilla and Grant (1985) demonstrated that the ability of the nurse to help the patient with needed changes and adjustments as a result of illness was significantly correlated with psychological well-being and the quality of the patient's survival. Siblings who received more communication and support perceived their lives to be less affected in alleviating problems and their quality of life improved (Havermans, Eiser, 1994).

## Conclusion

Interlink Community Cancer Nurses is a model program which patients described in a program evaluation conducted in 1996 as making a significant difference in their experience with cancer. Ninety-eight per cent of cancer patients surveyed identified the Interlink program as an essential service that should be available to

people from early diagnosis and throughout the continuum of cancer. The Interlink program model demonstrates that nurses can make a difference in the experience of patients and may contribute to savings within the health care system through a potential reduction in hospital readmission rates and reduction in psychiatric morbidity. Further research is critical to determine the effectiveness of specialist nurse models of care delivery in the community and particularly to determine the effectiveness of the independent nursing model of Interlink supportive care on patient outcomes.

The impact of cancer nurses in facilitating an individual and family's journey with cancer cannot be underestimated. Interlink Community Cancer Nurses is an essential program that provides supportive care to people with cancer and their families in the community. The care provided by expert oncology nurses through the Interlink program is poignantly captured in the following statement made by a patient:

*These nurses make an unbearable situation bearable.* ♡

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