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Patient Navigation in Cancer Care



Final Report

Sociobehavioural Research Centre
BC Cancer Agency
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EXECUTIVE SUMMARY

Cancer is a burden experienced by patients and their care providers throughout the full trajectory of the disease. Challenges include a myriad of physical, social, emotional, nutritional, informational, psychological, spiritual, and practical needs. In the current health care system, cancer patients report fragmentation of service, delays in access, lack of coordination between providers and inadequate information.

Timely access to informational and emotional support around the time of cancer diagnosis is crucial in helping patients adapt and prepare for their journey in navigating the health-care system.

The Canadian Strategy for Cancer Control, a consortium of stakeholders from across the country, identifies coordination of services as a key component in improving cancer care in Canada. To meet patient needs, the BC Cancer Agency (BCCA) has also identified the integration of cancer control programs in the community as a primary organizational objective. An imperative is to create models of integration and coordination using test-sites, with the intention of developing community-based approaches for cancer control. In the reported study, the Sociobehavioural Research Centre (SRC), located within the Provincial Rehabilitation Network of the BCCA, applied an evidence-based approach to the investigation of facilitative Patient Navigation models.

The term '*Patient Navigation*' denotes a system or professional role primarily intended to expedite patient access to services and resources, and improve continuity and co-ordination of care throughout the cancer continuum. Navigation should seek to address patients' informational, emotional, and practical needs during the cancer journey.

Project Description

The work described in this report comprised two phases. Phase 1 had the specific objective of articulating a model of Navigation, informed by the needs and perspectives of different stakeholders, clinical practice, and research literature. Phase 2 focussed on development and piloting of tools and methods, with specific objectives to: identify theoretically- and clinically-relevant outcomes; develop instruments that could be used to structure the Navigator intervention and measure outcomes; and pilot-test in two practice settings the developed instruments and the feasibility of conducting a rigorous empirical evaluation design.

Phase 1

The team held a series of consultations with informants and stakeholders, including patients, oncologists within the BCCA, researchers in nursing and community health, decision-makers in regional health authorities, and family practitioners. To develop a framework, the team reviewed bodies of literature on social support, readiness for change, coping, and self-efficacy. From the discussions and literature review, the project team identified a range of potential outcomes from Navigation interventions.

In addition to coordination and integration functions, the research team determined that 'patient preparedness' should be a core outcome and function of the Navigator role.

Phase 2

The team focused on a small subset of outcomes for which to develop and field test instruments. Validated instruments were used where possible. Several instruments were developed to measure outcomes of practical and theoretical significance. In addition, an assessment tool was developed to assist the Navigator shape an individually-tailored intervention and to collect data on patient needs systematically.

To test the feasibility of a prospective, controlled design, which could potentially produce the strongest method for testing effectiveness, the project team conducted a small study in the two sites to 1) pilot the questionnaires, and 2) test the feasibility of using a quasi-experimental evaluation design.

The objective of the feasibility study was to answer a number of methodological, operational and program questions, to provide the basis for the design of a larger, regional survey, and future evaluation studies.

In addition, the goal was to determine whether the questionnaires developed were acceptable in terms of length, ease of understanding and timeliness. Given the short period available, a test of the effectiveness of the Navigation interventions was not conducted.

In two project test sites, the team engaged Navigator informants from separate programs: one situated in an urban setting within a Breast Health Centre, led by a breast-health nurse; the other in a rural region led by a social worker, assisting cancer patients with all tumour sites.

In general, the methodology consisted of selecting a sample of patients around the time of diagnosis and before consultation with a surgeon or other oncology specialist. The time window was selected as that when patients are at highest risk of experiencing distress, and when the Patient Navigator may have the most beneficial impact.

Research Findings

Although the sample size was small, findings from the feasibility study were found encouraging, specifically:

- 1) the questionnaires had good acceptability, were easy to understand and required short time for completion;
- 2) the response rates were good;
- 3) the tools can be used for future studies to test reliability and validity.

There were differences between the Navigation programs and in the backgrounds of the Navigators; however, each Navigator spent a similar amount of time with patients and provided similar services.

In both programs, patient needs most often identified were: psychosocial support, help with understanding medical information, help communicating with others, and practical support.

Family physicians were sampled to obtain an understanding of their perspectives on and preferences about the Navigator role, including how they would like to work with Navigators. In summary, these data indicate that the majority of physicians sampled do currently engage in some Navigator functions, but would value additional support of a cancer Navigator.

The findings support the importance of the general practitioner's role, and indicate that family practitioners would prefer to share Navigation responsibilities with other professional Navigators. The sample of doctors was small, however, and the findings may not be generally representative.

Conclusions

A conclusion of this study is that Navigation should not be approached too narrowly or rigidly.

Navigation work differs in diverse settings, and can be enacted by different professionals, who will differ in how they provide emotional and informational support, depending on population and specific health-system context.

A singular model of Navigation is consequently not recommended, although Navigation should be in all cases systematic.

The following core characteristics are recommended in order to structure future Navigation interventions:

- intervention should be time limited and targeted to high risk phases and service delivery gaps;
- patient needs for information, support and practical help should be assessed;
- intervention should have the goal of 'patient preparedness';
- information should be paced;
- intervention should be supportive, but not psychotherapeutic.

The study data must be viewed with caution, since the pilot sample does not allow for strong conclusions. More studies are needed to test these questionnaires at a larger scale and with a controlled design.

Based on the results, however, the following conclusions were drawn:

- The theoretical framework and clinical model have face validity, and are clinically relevant and practical. They can be used by others involved in Navigation work, and should be tested empirically.
- The tools are useful and acceptable to patients and clinicians. Two of the developed tools in particular, the Patient Preparedness Questionnaire T1, and Patient Needs Identification Tool can direct and focus Navigator activities for individual patients, and in addition can be used as data collection instruments.
- The quasi-experimental design proved challenging to implement in a community setting, and if future work is to be conducted, the research team will need to be composed of investigators in different health jurisdictions, focusing on a small piece of Navigation.
- Including the family physician in Navigation work, including research, was identified as having potential value.

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1 INTRODUCTION

1.1 The Need for Patient Navigation

The need for improved access, integration, coordination and continuity of care

Primary, secondary and tertiary care is growing exponentially in Canada, with an increase in cancer prevalence of 70% expected by the year 2015 (Canadian Cancer Statistics 2002). The increasing demand for cancer care, in part based on changes in demographics, will have a major impact on services, manpower, and costs in the health-care system. If demands are to be met, the challenge will be to develop innovative mechanisms able to address access, co-ordination, and continuity of care.

Cancer is now recognised as a chronic illness, with some estimates predicting that over 50% of patients will survive the disease. Typically, individuals with chronic diseases move frequently between primary, secondary, and tertiary care settings, resulting in fractured care, unmet needs, frustrated caregivers and compromised outcomes. Primary care practitioners are severely constrained by levels of training, resources, patient load, experience, time, and timely access to relevant information with which to address chronic diseases adequately and improve outcomes.

The development of an integrated, coordinated system of cancer care that ensures optimum access and continuity of care has been identified as a serious challenge for cancer control in Canada.⁽¹⁾

A recent study in BC has also described a system of care lacking critical features of communication, coordination and continuity.⁽²⁾

In the current system of care, cancer patients experience service fragmentation, delays in access, lack of coordination between providers, and inadequate information.^(2,3) Such poor communication and coordination, combined with lack of access to supportive care during critical times, and the sense of isolation that is a consequence of fragmented care cause patients to express frustration and anger.⁽⁴⁾

Primary care professionals are typically charged with the coordination of care for patients and their families in communities. However the role in cancer care of these professionals, particularly for the family physician, is often unclear. Providing support for the family doctor in evidence-based cancer care is also fragmented.

Family physicians have a crucial role to play in helping patients meet the spectrum of needs across the cancer continuum, and in providing much-needed continuity and co-ordination. However, their role lacks definition, and they are under-utilised. As a result, family physicians may question whether they are active members of the cancer care team.

Continuity is especially significant in the cancer context, as care is often intense, distributed among a wide range of service providers, and lengthy, from initial diagnosis through treatment to cure or palliation.⁽⁵⁾

Continuity of care and an unrushed consultation are considered important to cancer patients and their providers, and discontinuity is perceived to lead to a lack of personal and case familiarity and communication difficulties.^(6, 7)

Pressure to implement more integrative models of care and provide access to a seamless continuum of service comes from policy-makers' desire to improve quality of care while cutting costs. In addition, many patients and families are dissatisfied with poor communication and co-ordination between health providers, and the sense of isolation that is a consequence of fragmented care. The problems of discontinuity and lack of co-ordination of cancer patients are underscored by the results of a recent study

which found that the number of doctors encountered by patients during the cancer experience ranged from a minimum of 13 to an astonishing maximum of 97, with a median of 32.⁽⁸⁾

Unfortunately, there is a lack of research-based evidence to support the use of any particular model to overcome these challenges,⁽⁹⁾ although specific strategies have been recommended, such as concentrating care with as few providers as possible, providing consistent management, and including psychosocial care of patients and families.⁽¹⁰⁻¹³⁾

Psychological impact of cancer

The diagnosis and treatment of cancer may result in severe psychological morbidity for patients and their families.⁽¹⁴⁾ Generally, the impact of cancer diagnosis is affected by the social connotations of this disease; namely death, disfigurement, dependence on family, disruption of relationships, disability, and pain.

Holland and Goen-Piels⁽¹⁵⁾ describe the psychological and emotional reaction to the diagnosis of cancer as having three distinct phases. On hearing the news of cancer, the first phase is characterized by disbelief, avoidance, and denial. For some patients the reaction is despair rather than denial, particularly when they have lived with fear of, or have expected to develop cancer. The second phase, where patients begin to recognize the reality of the diagnosis, is described as one of emotional changes and dysphoria. In this phase patients are often depressed and anxious, finding it very difficult to carry on their daily routine. This period may last for a week or two, the distress then dissipating with the beginning of treatment and the realization that something can be done. The third phase comprises a long-term adaptation to the diagnosis and treatment of cancer. During this period, patients return to daily routines, and may use coping strategies to manage distress.

While this cycle of disbelief, dysphoria, and adaptation recurs with each new crisis in the cancer journey, patients experience the highest distress at the time around diagnosis and before consultation with specialists.⁽¹⁶⁾ Adaptation to cancer depends on a variety of factors that interact and can affect the clinical outcomes and quality of life of the patient-family unit. These factors can be personal (such as coping

skills, and personality); societal (social support, or beliefs); and disease-related (the stage of disease, or symptoms).

It is known that two-thirds of cancer patients will eventually adapt to their illness. Identified factors associated with good adaptation include having reliable social support, personal positive attitudes, fighting spirit, and positive coping skills. By contrast, the one-third who fail to adapt commonly report low levels of social support,^(17,18) poorer functional status,⁽¹⁹⁾ and poorer medical outcomes.⁽²⁰⁾ Furthermore, patients suffering emotional distress have more difficulty making decisions about treatment, seek more medical consultation, and are less satisfied with their medical care.

A wide spectrum of physical and emotional stressors have been identified as critical contributors to high psychological distress among cancer patients. For instance, Larouche and Edgar⁽²¹⁾ analysed responses from 224 cancer patients to a self-administered questionnaire about psychosocial distress, and found that emotional, spiritual, informational, family and practical problems were identified as causes of distress by 42% of participants. For the remaining 58% of patients, physical symptoms were the main cause of distress.

These findings underscore the need for 1) providing comprehensive, holistic care for cancer patients and caregivers; and 2) making these services accessible to patients close to home. While other sources of support may be available in communities, patients often lack knowledge of such services, or learn only after completing treatment, when their need is less.

In summary, although most cancer patients will eventually adapt to the diagnosis, about 30-50% will suffer significant emotional, psychological and social distress, with at least 25-30% meeting the criteria for either a major depressive disorder or adjustment disorder with depressed mood.⁽²²⁾ Psychosocial interventions are now known to be effective in addressing many of the psychosocial and practical problems identified by patients as stressors.

Timely access to informational and emotional support around the time of diagnosis is crucial in helping patients adapt to their new circumstances, and be

better prepared for navigating the health care system.

Failure to recognize and treat these patients with high emotional distress may jeopardize cancer-care outcomes, decrease patient and family quality of life, and increase health-care costs.

Patient Navigation as a potential solution

The term '*Patient Navigation*' is a relatively new one within the Canadian health care system, although the notion is not. The term is used to denote a system or professional role primarily intended to expedite patient access to services and resources, and improve continuity and co-ordination of care throughout the cancer continuum.

In a recent literature review commissioned by the Canadian Breast Cancer Initiative (CBCI),⁽⁸⁾ the following terms were used to describe what is in essence the professional Navigator role: Case Manager, Clinical Coordinator, Cancer Support Nurses, Follow up Nurses, Advanced Nurse Practice, Breast Specialist, Breast Nurse and Breast Cancer Coordinator. These terms in fact capture narrow aspects of the Navigator role. Patient Navigators do more than expedite patients through the health-care system. In practice, they provide an umbrella of supportive care.

For example, primary-care nurse Navigators located in cancer centres oversee the treatment process, provide information and support to the patient, link with other professionals in the treatment process, and act as a single, constant contact. In this role, they provide psychosocial care to patients, and relieve pressure on the oncologists.⁽¹³⁾ A community Navigator located outside cancer centres links people to formal and informal resources. By co-ordinating efforts so that a patient receives psychosocial supports, home care, and information, patients are helped to develop effective coping strategies that maximize healthy functioning.⁽⁸⁾

It is well established that cancer patients may experience psychological difficulties, but psychological and psychiatric morbidities are generally not assessed,^(23, 24) and patients are seldom informed or referred to formal support networks. Informal networks, family and friends are often not acknowledged by health-care

professionals, nor integrated into the care of patients.⁽²⁵⁾ However, a Navigator can serve the function of linking patients with these networks. Helping a patient access the many support networks that exist outside of the formal health-care system increases adjustment and quality of life.

Another function that a Navigator can provide is that of facilitating and assisting in decision-making. There is an established philosophy in health care that while responsibility is shared between patient, family, and multiple health-care providers, the patient exercises ultimate authority and must make critical decisions along the path to care.⁽²⁶⁾ Indeed, many patients do not wish to hand over decision-making control to their physician.⁽²⁷⁾ Knowledge of the right course of treatment is discovered through sustained dialogue, which may not occur in the doctor's office, but can occur with a Navigator who has established trust and rapport with the patient.

Navigation also includes an advocacy role, which again is one that extends beyond simply expediting the patient through the system. Advocates try to ensure that the quality of medical care is optimal, and that the patient is helped toward rehabilitation and psychological adaptation also. In the context of breast cancer, advocacy includes meeting informational needs, patient-physician communication, choice of primary surgical treatment, reconstructive surgery, adjuvant therapy, and addressing psychosocial issues, and employment and insurance problems.⁽²⁸⁾

Thus, broadly conceived, a Patient Navigator can be understood to be any person who assists the patient as an advocate, educator, and support-person throughout the illness experience, preparing them for procedures, and linking them with networks of professional and volunteer helpers.

In doing so, patients are not only assisted through the health-care maze in a more timely and effective fashion, but their psychosocial well-being and quality of life may be significantly enhanced.

Roles and approaches to Patient Navigation in Canada

In Canada, Navigation programs are known to have existed or continue to operate in a number of provinces: Quebec, Nova Scotia, Ontario, Manitoba, the Yukon, and British Columbia. In Nova Scotia, the number of patient Navigation programs has recently increased: five of nine health authorities employ a full-time Navigator to provide service under the coordination of Cancer Care Nova Scotia. In Quebec, three university and two regional hospitals have well-established programs that have been integrated into primary-care nursing programs.

In an environmental scan commissioned by the Canadian Breast Cancer Research Initiative, Farber, Deschamps & Cameron⁽⁹⁾ identified three Navigation approaches in Canada: *Active Co-ordination*, *Facilitating*, and the *Shared or Tacit* approach.

The Active Co-ordination Model, usually nurse led, described the Navigator largely as filling a direct, proactive co-ordinator role. The role involved activities such as directly arranging and making appointments for the patient; completing and transmitting forms; and contacting potential referral sources. It included direct contact with the physician, and in some cases, only contact with the physician. In addition, the Navigator provided the patient with education and assisted to some degree with decision-making.

The second model, the Facilitating Navigator Model, was more psychosocial in emphasis, and tended to be either professionally or volunteer led. The Navigator working from this approach focused more on educating and informing the patient, and assisting in decision-making, with little direct co-ordination. The Navigator would act as a consultant, and might offer suggestions and recommendations, but the patient was responsible for pursuing necessary action.

The authors of the report noted that the former model was based on a "doing for" approach while the latter represented an "empowerment" approach. In the former, the Navigator "does for" the patient, a role which is congruent with the traditional medical/nursing approach. As the authors point out, this approach fosters dependency. In addition, it emerged from the environmental scan that the most frequently reported barrier to carrying out the role adequately was limited resources, and burn-out as a consequence of role overload often

reported. In contrast, an empowerment model focuses on training the client to help her/himself by providing information, encouragement and support.

Third, the Shared or Tacit Model was less clear in formulation, but involved several people providing Navigation either tacitly or by design. The enormity of discontinuities and lack of co-ordination, as well as the value of having input from different providers, may warrant the use of multiple Navigators. However, the results of the scan suggest that under this model, patients were more vulnerable to falling through the cracks.

Thus the CBCRI report brought some clarity to the question of 'what is a patient Navigator?' in the context of cancer care in Canada, and identified approaches to Navigation. However, it is apparent that there is no common understanding of the limits of the role or core Navigation functions. The authors noted that Navigators tended to take on increasing responsibilities, and often burned out.

Evidently needed is an elaboration of a preferred or 'best practice' model. In order to establish a model which defines the boundaries of the role, certain questions arise. What should be considered core features, appropriate to any project seeking to establish a Navigation program? What functions should be developed systematically and deliberately, rather than emerge on the basis of individual Navigator skills and the needs of a particular community, as perceived by the Navigator? These were some of the questions the research team sought to address.

1.2 Purpose and Objectives of Study

Following a series of stakeholder meetings in 2002 and 2003, the Canadian Strategy for Cancer Control (CSCC) identified five priority areas for implementation, one of which was to "rebalance focus", that is, to improve resources and systems for delivery of supportive care, rehabilitation, and palliative care. Patient Navigation was introduced as a priority strategy to address problems associated with rebalancing focus.⁽⁴⁾

The BC Cancer Agency (BCCA) identified the integration of cancer control programs in the

community as a primary organizational objective.⁽¹⁾ An imperative was to create models of integration and co-ordination using test sites, with the intention of developing community-based approaches for cancer control in other regions in the province. The BC Cancer Agency has been interested in approaches to Navigation for some time.

Patient Navigation was identified as a priority action by the BC Yukon Chapter of the Canadian Breast Cancer Foundation following their "Gap Analysis" project⁽⁵⁾, where both breast cancer patients and practitioners identified the need for 'Navigational assistance' for breast cancer patients faced with a fragmented and complex health care system.

The Sociobehavioural Research Centre, located within the Provincial Rehabilitation Network of the BC Cancer Agency, urged an evidence-based approach, and took on the role of investigating different strategies for patient Navigation. Previous work on Navigation (the CBCRI report⁽⁶⁾) has highlighted the relatively scant research evidence or conceptual clarity behind existing programs. Notably, there is no evidence to support the use of one Navigator model over another, and of the few Navigator programs that had been evaluated at the beginning of this project, only patient satisfaction and qualitative/anecdotal data had been documented. Although most Navigator programs reportedly collect data, there had been no data linkage to predicted or desired outcomes, or even a plan of how the data might be used.⁽¹²⁾ Thus, current experience had done little in delineating a best-practice approach based on evidence.

The need for clarity and rigorous evaluation is particularly important given the growing momentum of Navigation approaches. Tight fiscal barriers and the need for programs to be evidence-based require that new methods be developed systematically, and rigorously evaluated. Furthermore, Navigation should seek to address patients' informational, emotional, and practical needs during the cancer journey. The Navigator role is often described as one of case management, but it could go further and be explicitly psychosocial in orientation.

The long-term objective of the current research program is to contribute to an evidence-based national approach to Navigation.

The BC work described in this report is comprised of a Phase 1 (clarification of a model) and Phase 2 (development and piloting of tools and methods). Later phases should involve collaboration with others involved in Navigation work, and eventually effectiveness testing within a randomised control trial methodology.

Phase 1 objectives were to articulate a model of Navigation that was informed by:

1. the needs and perspectives of different stakeholders, including patients, oncologists, family doctors, and decision-makers from regional health authorities;
2. clinical practice – behaviours and functions fulfilled by health professionals as they enacted and evolved Navigator roles;
3. research literature – developing evidence on psychosocial/supportive care needs of cancer patients, and evidence-based theories that could inform and guide the practice and evaluation of a psychosocial Navigation model.

Phase 2 objectives were to:

1. identify theoretically- and clinically-relevant outcomes;
2. develop instruments that could be used to structure the Navigator intervention and measure outcomes;
3. pilot-test the instruments and the feasibility of conducting a rigorous empirical design in two practice settings.

2 CLARIFICATION OF A NAVIGATION MODEL

2.1 Information Gathering from Stakeholders

The Navigator functions in a bridging role, and therefore must be able to negotiate or reconcile what are sometimes competing stakeholder needs. Throughout the research process, the team held a series of consultations with informants and stakeholders in Navigation, including patients, oncologists within the Cancer Agency, researchers in nursing and community health, decision-makers in regional health authorities, and family practitioners.

These discussions sensitized the research team to different needs of stakeholders, and influenced our understanding of optimal Navigator functions. While these consultations cannot be

considered exhaustive or unilaterally representative, they were useful in broadening our view. The following perspectives, of patient, health provider, health system, and family physician, captured the most important themes emerging from these discussions.

Patient perspective

Of several themes identified, one of the most significant related to the need for an overview of the patient journey – hence the metaphor of ‘navigation’. Post-treatment patients reported that if they had had more knowledge of what lay ahead, they might have made better decisions and experienced less suffering. They expressed how valuable a ‘map’ of the terrain ahead would have been.

Another recurring theme was the need for a more human encounter during the cancer journey. Some patients were angry with doctors who they felt should have intervened or assessed

earlier; others felt that their doctors were too busy to listen, that patients and doctors were given insufficient time to ask questions, or that only medical information was provided and many other concerns were not addressed.

Health provider perspective

The primary theme that emerged through discussion with physicians was the need for patients to be better prepared for consultation. Oncologists and surgeons we spoke with recognized that patients were often overwhelmed with the news of diagnosis and the sheer volume of information provided. Without a basic understanding of the issues, patients were ill-prepared to make the most of their doctor's expertise during the consultation. When patients knew too little they could not engage in meaningful discussion; whereas when they were 'over-' or ill-informed, doctors spent their time addressing issues which might not be relevant but were of great concern to the patients.

Health system perspective

Themes that recurred in discussion with administrators and researchers sensitized to health-system challenges were related to efficiency and sustainability of the role. Concerns were raised about the wisdom of introducing another layer into the system; and in particular of introducing a new professional role whose job would be, in essence, to patch gaps between the domains of others. Another concern related to funding cancer-specific Navigators. If funded by regional health dollars rather than the provincial cancer budget, then Navigation would need to be relevant to all chronic diseases.

Family physician perspective

The research team engaged in consultations with the co-director of the Family Physician Oncology Network, and learned that many GPs considered they currently fulfil Navigator functions, and are best positioned to take on the role over the duration of diagnosis, treatment and follow-up. However the current funding structure creates a financial disincentive to providing such care, as does the need for specialized knowledge. The theme that emerged was the potential benefit of assisting family physicians in their Navigation functions; and for dedicated Navigators and physicians to establish good communications.

Outcome of consultations

Out of these consultations, the notion of 'patient preparedness' emerged. Patients have a need to understand the sequence of likely future events and outcomes, which Navigators seen shortly after diagnosis could provide. Yet the patient's 'need to know' must be tempered by the reality of cancer, namely, that health providers cannot in any given case predict the road ahead with much certainty. Only general pathways and schemas can be identified. However, in the short term, patient and expert consultant benefit when the patient understands the meaning of the information contained in their chart, and can engage in discussion about specifics and the immediate sequence of events. Navigators would therefore benefit both patients and doctors by coaching patients about proximate events, such as the next consultation or procedure, and helping them develop a longer term sense of future events, while allowing room for the uncertainties.

The consultations reinforced the understanding that patients need an opportunity to talk through the circumstances and details of their diagnosis and illness in an unhurried and caring environment. Verbal processing is an important aspect of becoming prepared. Thus, in addition to the coordination and integration functions identified elsewhere, the research team determined that patient preparedness should be a core outcome and function of the Navigator role.

The consultations also raised two issues that were beyond the scope of the current project, but should be addressed in future work:

- the structural aspect: how to facilitate interaction of Navigator and Family Physician for optimal outcomes and efficiencies; and
- the political and economic aspects: how to position the Navigator role within particular regional and institutional contexts, so that it may be fully utilized as an essential and sustainable service.

2.2 Identification of Best Practices in Two Navigation Programs

The CBCRI report and environmental scan identified that most Navigation programs developed from grass root origins, evolving as individual Navigators helped cancer patients using skills and resources at hand. While this approach has its limitations and challenges (principally that practice is determined by individual interpretation of patient needs, rather than evidence), it has a strength: the Navigator is often best positioned to identify with precision what is needed in an individual practice setting. Much can be gained by simply observing competent Navigators in practice, and learning what they do. From this, it is possible to discern particularly effective functions and characteristics, representative therefore of 'best practice'.

Background of the two Navigation programs

Early in the research, the team engaged two Navigator informants from separate programs as project test sites. The programs investigated were in two of British Columbia's five regional health authorities (*Appendix 1*): the Vancouver Island Health Authority (VIHA); and the Kootenay Boundary region (KB).

Prior research in both regions had established the need for better coordination and integration of care for cancer patients. In each case, interested health professionals and institutional support was available to facilitate collaboration. In the VIHA, a nurse in a case-manager role sought to enhance her role by providing more psychosocial care; in KB, a medical social worker had been hired with the explicit objective of developing a new Navigator program. At the inception of this project, an investigator was designated to engage in dialogue with the Navigator and health professionals in each Navigation program. The research team were interested in clarifying what the professionals perceived as the main aspects of their role; what were the most important patient needs; and what they were doing to meet them. Information was shared between investigators and Navigators regarding: outcome of consultations;

research literature findings; and Navigator judgements regarding best practice and patient needs. This iterative process led to mutual learning, and enhanced the relevance of the research.

The VIHA program was situated in an urban setting, within a Breast Health Centre, and led by a breast-health nurse who provided a Navigation service to breast cancer patients. The mandate of her program was to offer compassionate, quality care, focused on each breast cancer patient's needs. The program was fully-funded by a Canadian Breast Cancer Foundation donation. In the VIHA, a Navigation Steering Committee was formed in May 2003 to oversee research issues related to the program. Members of the committee included a wide range of health professionals: a general surgeon (private practice), an oncologist, a patient and family counsellor (BCCA), a chemotherapy nurse, two health-data analysts, the manager of the breast-health centre, the Navigator (VIHA), and the project team's designated investigator.

The KB program was situated in a rural region covering many thousands of square kilometres of winding roads and mountain passes, and was led by a social worker. Travel for patients and health professionals was a major challenge and a directing factor in how her role was conceptualized. The mandate was to help male and female cancer patients and their families across all tumour sites by providing information and emotional support, and where possible linking them with existing services. The position was jointly funded by the regional Health Authority and the BC Cancer Agency.

In the KB, the designated investigator communicated with the region's Navigator on a regular basis, and participated via conference call in the KB Navigation Program Advisory Committee. Members of this committee included a general practitioner, Director of Community Care, hospice coordinator, primary-care nurse, acute residential nurse, social worker, patient representative, and the regional coordinator of the Canadian Cancer Society.

Thus, in both cases, the researchers worked at some distance from programs and roles already defined. An important difference between programs was that VIHA had been in operation for two years prior to the research, and the Navigator had established links within the community. By contrast, the Navigator in the rural region initiated work as the research

itself began, and was not well known within the community. Ensuing consequences for the research will be discussed later.

Vancouver Island Health Authority Navigation practice

The VIHA Navigator maintained a network of health-related professionals in different sectors: within hospitals, the BCCA Vancouver Island Cancer Centre, and the Canadian Cancer Society and Canadian Breast Cancer Foundation. From this broad network she was referred patients, and in turn linked patients with professionals as appropriate.

The Navigator generally contacted the patient (in person or by telephone) at four critical points during the early stages of their cancer journey:

- 1) during the interval between confirmation of the diagnosis and the first consultation visit with the surgeon;
- 2) prior to surgery;
- 3) follow-up: 2-3 days after the operation;
- 4) after the surgical pathology report became available, and before the patient's first visit at the BC Cancer Agency.

The Navigator provided a wide range of services at each contact point, with usually a different focus depending on the patient's specific needs and concerns.

During the first contact, the Navigator represented a compassionate and knowledgeable professional with whom patients could talk about their concerns and distress, if any. Generally, the services offered were:

- assisting patients to become familiar with the health care system, and providing them with an overview of the care journey;
- coaching patients in preparation for a quality interview with their surgeons;
- preparing patients for decision-making over treatment options, while respecting their choices;
- providing patients with expert advice in the use of guide books, or providing them with an overview of key sections;

- introducing them to supports where needed.

During the second contact, the focus was to:

- confirm understanding of surgical choice and operation date;
- assist patients to become familiar with hospital admission and discharge procedures;
- prepare patients for post-operation discomfort, and teach management strategies;
- help patients access resources for emotional and practical support where needed.

In the third contact, generally brief, the Navigator provided encouragement and checked on post-operation discomforts.

During the fourth contact, the Navigator:

- provided encouragement and support for recovery;
- encouraged patients to attend post-breast-surgery education sessions;
- prepared patients for the visit to the Vancouver Island Cancer Centre.

The VIHA Navigator compiled and organized a large number of information and support resources, and developed some of these herself. She also provided contact information about, and referral to, psychosocial supports available in the community.

Another aspect of the Navigator's role was to build relationships with the eight surgeons performing breast cancer operations in the region. She cultivated good rapport with the physicians and their medical office assistants. These professionals reported confidence in the positive contributions the Navigator made as a member of patients' cancer care teams. The surgical offices refer a significant number of patients to her.

Lastly, the Navigator is well versed in the health system processes related to breast cancer treatment and care. She also participated in work projects that aimed to clarify and develop breast cancer road maps. She built it into her intervention by helping patients to become prepared for the journey ahead. Thus she built

projects into her role that helped the system work better, as well as providing direct care.

Kootenay Boundary Navigation practice

In the KB program, the Cancer Care Navigator worked under the broad direction of a multidisciplinary Advisory Committee, its members being based in different areas of the region. In order to build community resource capacity, the Cancer Care Navigator worked with a network of health professionals in various communities, the Canadian Cancer Society, and volunteer groups. In addition she collaborated with the project team to integrate perspectives and develop practice adaptations.

The Navigator actively promoted the program by working with the health authority media department, by making regular presentations about the Cancer Navigation program to family physicians, surgeons and oncologists at their rounds throughout the region, and to social workers and activity workers in hospitals. These presentations included descriptions of the program and services, and the support expected from other professionals. She also operated through a group of point-person nurses in primary health care centres in the smaller communities. Apart from acting as the Cancer Care Navigator's contact in the community, the point-people helped patients from outlying areas to learn about the program. Finally, through her active involvement in community program development, the Navigator established working relationships with local health-care professionals who, in turn, advertised the Cancer Care Navigation program.

The Cancer Care Navigator generally contacts patients (in person or by telephone) at several key treatment stages of their cancer journey.

For newly diagnosed cancer patients, the Navigator:

- offered counselling support regarding the impact of receiving a cancer diagnosis;
- helped patients prepare themselves for treatment visits with specialists, and to the regional Cancer Centre;
- facilitated problem solving by patients in relation to decision-making, financing, transportation, and relationships;

- provided information about and directions to resources;
- referred patients to community supports.

For cancer patients undergoing treatment, the Navigator's service focused on helping patients to increase knowledge and obtain support from community professionals through:

- linkage to support groups, enabling patients to have a sense of belonging and to share experiences with people who understood them;
- referrals to exercise, nutrition, or relaxation programs, which reduce fatigue and treatment side-effects, and enhance quality of life.

For post-treatment cancer patients who often felt isolated in the community, the Navigator emphasized linking patients with support groups and coping strategy programs. For newly-diagnosed palliative cancer patients, the Navigator provided these services:

- helped patients and their care-givers to access community resources and services;
- provided emotional counselling and facilitated planning for the end of life;
- referred patients to hospice programs.

Immediately after she was hired, the Cancer Care Navigator conducted a needs-assessment of the region, an area with geographically dispersed small rural communities. Development of community resources to complement the work of the Navigation program was identified as a priority need. The Cancer Care Navigator has worked persistently in this direction, either directly developing community programs or facilitating their development as a key team member.

The following new programs were developed during her first year:

Patient support groups

The Navigator developed several cancer support groups attended by patients in treatment and post-treatment. In a remote area of the region, she taught a workshop in Facilitator Skills for Group Leadership, using a train-the-trainer model. Participants included nurses and other health professionals, several of whom began new patient support groups.

Professional support group

The Navigator organized a support group for health professionals from different areas of the region. These are people who tend to work without colleagues, often caring for patients they know, and are vulnerable to burnout. The group is attended primarily by chemotherapy nurses. A training program was also created to support hospice volunteers.

Exercise/nutrition/relaxation program

The Navigator organized a committee of professionals from multiple communities, who deliver chemotherapy, physiotherapy, physical training, healing, and program-evaluation, in order to develop an exercise/relaxation/nutrition program for chemotherapy cancer patients.

Dragon Boat Team

The Navigator took an active role in developing a Dragon Boat Team for cancer survivors – primarily breast cancer survivors. The program received strong support from women cancer survivors and the public, including the involvement of an experienced coach, a fitness trainer, a physician, and the local media.

Drumming circles

This program was developed initially for a group of cancer patients. Over time, individuals with different health conditions joined, and it has evolved into one of the most popular and appreciated programs.

In summary, two different Navigation programs existed prior to, and were functionally independent of, the Navigation Research project. These two programs differed in terms of the practice setting of the Navigator, the population being served, and in the professional background of the Navigators. Over the course of the study, the team examined the experiences of the programs in order to identify characteristics of each clinical model.

2.3 Identification of a Psychosocial Theoretical Framework

So far as we know, Navigation work in Canada has not been explicitly informed by

psychological research. As stated earlier, the team intended to clarify a model that placed the Navigator's services within a framework encompassing not only expediting access and improving coordination, but including a strong focus on 1) provision of psychosocial support, 2) individualized service interventions, and 3) enhancement of patient self-efficacy.

The team reviewed four critical bodies of literature to develop a framework: a) social support; b) readiness for change; c) coping; and d) self-efficacy.

Social support

Social support has been conceptualized in many ways, including three highlighted features. The first feature is the structural aspects of social networks, such as the size of a person's social circle, or the number of resources provided. The second feature is the functional aspects of social support, which include emotional support, or a sense of acceptance. The third feature is enacted support or the provision of specific supportive behaviours, such as reassurance or advice, in times of distress, as well as the subjective perception of support by the recipients.⁽²⁹⁻³¹⁾

Support has been defined in a more interpersonal light as an exchange between providers and recipients. Three main types of supportive social interactions have been described: emotional, informational, and instrumental.^(11, 12) Emotional support involves verbal and non-verbal communication of caring and concern, and is believed to reduce distress by restoring self-esteem and permitting the expression of feelings. Informational support, which involves the provision of information used to guide or advise, is believed to enhance perceptions of control by reducing confusion, and providing patients with strategies to cope with their difficulties. Instrumental support involves the provision of material goods (such as transportation, money, or physical assistance), and may also help decrease feelings of loss of control.

The concept of social support is at times confused by the fact that support can emerge from both natural and more formal support systems.

Natural support systems include family and friendship networks. More formal support is

provided by professionals (such as mental health and medical professionals), through self-help of individuals with similar problems, and through social or community ties (such as clubs or religious groups). Presumably, natural support networks are a more enduring source of support, while other forms of support may be more transient. However, it is not clear which source of support is superior. Nevertheless, how support is conceptualized and mobilized may be critical in determining an intervention's ultimate success.⁽³²⁾

In the light of this literature, the Navigator is clearly a formal (transient) support provider, who may offer instrumental, informational, and emotional support to patients in care. Given that support systems for patients will already exist prior to the Navigator's arrival, it is critical for system cost-efficiency that expensive and possibly confusing duplication of support services is avoided.

There is convincing documentation, however, that wide gaps in such support provision exist, and the need to close them is what has triggered the call for professional Navigators. Inherent in these considerations is the recognition that an efficient Navigator's first task will be an assessment of support needs by identifying existing networks and services. Patients' needs for support will inevitably vary: an elderly woman living in a rural environment may have pressing transportation problems, whereas an urban patient may be a recent immigrant, handicapped by poor language skills and a lack of awareness of entitlements within the medical system. For the former, instrumental support is likely to be critical, whereas the latter may require more informational support.

Readiness for change

Theory with respect to readiness for change is helpful in deciding the needed type and sequencing of types of help and support. It may not be immediately obvious how readiness for change ties in with cancer treatment, because the readiness for change concept was initially developed to deal with quitting or reducing harmful addictive behaviours.^(13, 23) It is posited here that the medical care system, on a proper ethical basis, provides a patient with diagnostic services and proceeds to build a concrete treatment program emanating from the diagnosis, based on knowledge of disease status and progression. Although it may be in their best interests to accept and cooperate with

treatment offers, patients may not in fact be ready to engage in decision-making about treatment choices.

Anecdotal evidence and research on physician-patient interaction indicates that many patients are sufficiently upset about a positive diagnosis that they do not retain all information offered, and may then be unable to make prompt informed choices. Emotional distress leads to cognitive interference and to impairment in mental processing.^(33, 34) Some patients may understand the medical implications, but need to process what this diagnosis means for their own life plan, and for setting priorities; others will be concerned about which family member or friend should be informed about a positive cancer diagnosis, and how this might best be achieved. In sum, simply because the medical system desires the patient to act does not mean the patient is at the same point in decision-making.

Problem-focused and emotional coping

Also relevant to readiness for change is a rich literature on coping.⁽²⁴⁾ Types of coping are differentiated, that are efficient or inefficient with respect to the type of problem. Coping behaviours are divided into active and passive: active coping is problem solving, solution-oriented action; passive coping is more reflective, internal, and emotion-focused. Active coping is demonstrably more adaptive when problems are acute, controllable, and known solutions are available. Chronic health problems, however, cannot be readily fixed with a single course of action, and usually require emotional processing and acceptance.

When applying these concepts to a positive diagnosis of cancer, the choice of coping strategy will be significantly different when comparing, for example, the diagnosis of an early stage, localized melanoma with a metastasised, rapid progression cancer in the colon. The melanoma scenario has an excellent prognosis, quick action is of great benefit, and this can be easily made clear to patients. The example of the metastasised colon cancer, of course, marks the other end of this continuum and requires extensive emotional coping.

Recognizing and acting upon an appropriate type of coping is complicated by the fact that there are individual differences in preferred types

of coping, irrespective of the problem. Some people tend to see all problems as requiring emotional coping, while others tend to see all problems as concrete and resolvable. If all problems are seen as nails to be hammered down, it may be in the personality to provide the hammer.

Coping preferences can be readily assessed, and the resulting information can be used to understand patients and their unique approaches better. A popular tool for assessing coping preferences is the *Ways of Coping scale* by Aldwin et al.⁽³⁵⁾ A review of typical items exemplifies active and passive coping. Active coping items are: "Get professional help and do what they recommend", or "Just concern yourself with what to do next". Prototypical passive coping items are: "Try to forget the whole thing", or "Accept sympathy and understanding from someone".

Applying these lines of theorizing and research to the role definition of the Navigator means that Navigators need 1) to have a clear sense of the most suitable type of coping for a given situation (knowledge of cancer prognosis factors is critical); 2) to assess the typical coping preferences of a given patient, and 3) to learn about the intended choice of coping for individual patients in a given situation. If there is any mismatch between patient coping preference and best solution, the Navigator must move the patient skilfully through stages of decision-making and strike a balance acceptable to the patient, one which recognizes individual needs and best medical-care approaches. This may require facilitating the expression of emotional needs, and of non-judgmental, patient-centered processing of these needs.

It is suggested that successful manoeuvring through these stages will enhance the patient's quality of life, help the patient adhere to treatment regimes, and result in more efficient use of the health care system.

Self-efficacy

The fourth body of literature is work on self-efficacy and self-management. Self efficacy can be defined as the confidence in one's ability to bring about desired actions and

outcomes. According to this literature, enhanced self-efficacy leads to improved behaviour, motivation, thinking patterns, emotional well-being, psychological adjustment, and health status. Patients with high self-efficacy are less emotionally distressed.^(25, 26, 27) Research demonstrates also that self-efficacy can be enhanced through interventions such as adopting an exercise program, developing problem-solving and communication skills, and receiving emotional counselling.^(36, 37)

The concept of Patient Preparedness is not as theoretically well-established as the other constructs, but the research team became increasingly aware of its importance. Our interest emerged from discussions with health providers who viewed Navigation as a means of 'preparing' patients for consultation. Psychological preparedness refers to ways of enhancing an individual's sense of control, empowerment and readiness to respond to stressful situations, and several studies have examined psychological preparedness of patients for medical treatment.

Patient preparedness for cancer treatment can be described as being accurately informed of a diagnosis appropriate to the level of comprehension and complexity of the problem, together with having some understanding of the basic details of various tests, treatment options and outcomes.

It has been demonstrated that psychological preparedness can lead to reduced post-surgical complications, reduced time spent in hospital, a reduction in medication usage, and longer cancer survival time.^(37,38)

Specific psychological interventions that facilitate preparation include: offering behavioural coping methods to patients, providing them with relevant information, and teaching appropriate exercises, relaxation procedures, distractive techniques, and techniques to enhance control.⁽⁴⁰⁻⁴²⁾

According to findings from a doctoral thesis,⁽⁴³⁾ women who had undergone an operation for breast cancer most frequently cited incidents involving "receiving educational materials and/or information", and "getting support and

encouragement from others” as their most helpful preparatory experiences.

Relevance

The underlying constructs of these theories point to ways of enhancing the individual sense of control, empowerment, and preparedness in responding to stressful situations. This literature helped the research team define the roles of the Navigator operating within this expanded framework.

Ideally, the Navigator needs to:

- know what the disease prognosis is, and be aware of the patient’s disease knowledge;
- know the significant features of the patient’s physical and social environment, and the range of available services for informational, instrumental, and emotional support;
- support the patient in verbalizing emotional and practical needs;
- identify information and emotional gaps, and close them by activating the patient’s supports among family, friends, the community, and health professionals;
- provide adequate information, encourage confidence, and facilitate problem-solving and self-management strategies.

2.4 The Emerging Navigator Model

Both the literature and the clinical practice in the two BC programs highlight the critical role of facilitating patients’ timely access to information and emotional support.

Interventions encompassing this role are posited as having a positive influence on immediate patient outcomes such as level of anxiety, worry interference, as well as treatment decision-making. In the longer term such interventions affect quality of life, satisfaction with health services, and confidence in an ability to navigate the health-care system and manage one’s own

care. These, in turn, reduce the drain on health services. Therefore these characteristics were seen as important in an empowering model of Navigation.

Based on a synthesis of prior research work done on psychosocial supportive care and learning from the two BC Navigation programs, the project team identified characteristics of an emerging Navigation model for empowering cancer patients.

The research team identified four themes as being core to a psychosocial Navigation model:

(1) The intervention is driven by patient needs.

A core aspect of the intervention is helping patients to help themselves, while at the same time recognizing that timely access to appropriate information and services will ultimately assist patients in self-management. The questions that should be addressed by the Navigator and that should direct the intervention during the initial assessment are: “What are the patient’s current needs and capabilities?”, and “What can this patient and family do for themselves and what referrals will be helpful?” The Navigator’s task is to develop an individually-tailored intervention, depending on needs and resources, and paced in accordance with the patient’s treatment stage, and the informational and emotional readiness of that patient.

(2) The intervention is context- or community-based.

For Navigation to bridge gaps between the patient and the medical system effectively, the intervention has to be helpful in mediating specific disconnects in their unique context. The intervention must be flexible and responsive to local needs and strengths. In communities where resources are adequate and centralized, as in many urban settings, interventions can be more focused on the optimal provision of information resources for individuals. In communities where resources are scarce and dispersed, as in many rural settings (and where patients’ emotional isolation can be compounded by geographic separation), interventions may have to focus on emotional support and community development; and information may need to be indirectly provided, or be less specific.

(3) The intervention is time limited and targeted to high-stress phases.

The two BC Navigation programs demonstrate that a Navigator can realistically provide direct support for a limited time period only. It is therefore in the best interest of the patients and health system to have the interventions targeted at what have been identified as high-stress phases of the treatment trajectory, that is, at the time of initial diagnosis, immediately following treatment, and at the time of recurrence or a palliative diagnosis.⁽⁵⁾

On average, the two Navigators in the present study have between two and four contacts with each patient. Each contact lasts 30 to 90 minutes, and can be associated with two or three short phone-calls or email exchanges. Literature on chronic illnesses such as depression, suggests that patients receiving any variant of brief psychotherapy or professional support are likely to benefit, compared to those receiving only medical treatment.⁽⁴⁴⁾

(4) The intervention is outcome-focused.

Navigation has the goal of 'patient preparedness' for consultation, treatment, and coping. Preparedness involves the patient's mental and psychological 'readiness' to engage in active coping and decision-making. It incorporates two dimensions:

- the patient's basic knowledge of cancer and treatments: does the current information base facilitate or hinder understanding of cancer treatment options, or the ability to participate in decision-making;
- the patient's psychological state: does distress, anxiety, or self-efficacy affect the ability to process information, to understand issues discussed, or to participate in decision-making.^(33, 34)

Interventions in the studied programs involve conversations aimed at *a)* increasing knowledge; and *b)* facilitating patient decision-making and problem-solving, as they relate to treatment issues, emotional concerns, and practical cancer-related challenges of the patient.

It is understood that through sustained dialogue with the professional Navigator, the patient will learn additional information and be given the necessary time to integrate pieces of

information which until now may have been fragmented. The patient will then be able to formulate questions, and with the assistance of the Navigator, identify strategies for resolving them.

The Navigator, using empathy and listening skills, will facilitate a deeper level of discussion, giving the patient the opportunity to explore the likely sequence of upcoming events and the preparations that can be made for each stage. In addition, patients will be supported in discussing feelings and concerns that they may not have had an opportunity to acknowledge with family members or other health professionals.

Patient emotional and informational preparedness, and engagement in problem-solving should enable patients to become more capable of using the system effectively, to develop higher self-efficacy, and to experience greater satisfaction with care.

3 DEVELOPMENT & PILOTING OF TOOLS

3.1 Identifying Potential Outcomes and Measures

Once the characteristics of the Navigation intervention were identified, the project team proceeded with the identification of a range of potential outcomes from Navigation; selection of measurable and theoretically-relevant outcomes; and operationalizing of outcomes in measures and tools.

This phase of work involved moving from a broad range of possible measures to those that were seen to be directly linked to the Navigation model and desired overall outcome of 'patient preparedness'. It thus involved a process of identifying specific components of preparedness; components seen to be most relevant to what 'preparedness' and

'empowerment' would look like for cancer patients early in the cancer journey.

Clinical and health services outcomes

The project team developed a comprehensive list of clinical and health-services outcomes through an iterative process of brainstorming and discussion. This work involved the following groups: 1) investigators with diverse expertise in epidemiology, medicine, psychology, and social work; 2) the Navigators of the two BC programs; and 3) health professionals from the VIHA Navigation Steering Committee (a surgeon, an oncologist, a health administrator, and two system data analysts). The project team also reviewed outcomes identified in the Nova Scotia Patient Navigation Evaluation Framework,⁽⁴⁵⁾ and the Navigator Role environmental scan report.⁽⁸⁾ A comprehensive list of outcomes was finalized and sent for comment to two more oncologists at a BC

Cancer Centre in Kelowna, and to Peter Houts, Professor Emeritus, Pennsylvania State University.⁽⁴⁶⁾

The outcomes can be grouped into six categories:

- health providers' perceptions of the impacts of the Navigator role
- health-care resource utilization
- patients' subjective perceptions of the impacts of the Navigator role
- patients' observed behaviour as a result of interactions with the Navigator
- the Navigator's subjective perceptions of role functions
- the Navigator's documentation of time utilization, referral statistics, and role activities.

The project team decided to use the following selection criteria when choosing

outcomes to be measured during a full evaluation in a later phase of the study:

- outcomes should be objective/behavioural, i.e. not just self-reported perceptions
- outcomes should provide information about the cancer-care system, the patient, and the Navigator
- outcomes should be determined by the research objectives, i.e. they should describe Navigation and/or facilitate testing of intervention hypotheses
- it must be possible for the project team to obtain the relevant data.

From the range of potential outcomes, a subset was identified (*Table 1*). These outcomes determined the development of the evaluation and assessment measures.

Table 1. Patient Navigation: clinical and health-system outcomes

System	Patient	Navigator
Providers	Subjective	Subjective
Perceptions of family physicians, oncologists and nurses on: <ul style="list-style-type: none"> • Access to, and collaboration with, Navigator • Continuity of care • Patient benefits from Navigation service • Patient preparedness for meetings with specialists • Team effectiveness and collaboration 	<ul style="list-style-type: none"> • Physical discomfort/pain/fatigue • Sleeplessness • Anxiety/Distress • Sense of control • Depression • Self-efficacy • Perceived continuity of care • Family functioning • Social support 	<ul style="list-style-type: none"> • Workload: <ul style="list-style-type: none"> ◊ Number of patients seen ◊ Average number of contacts and amount of time per patient • Work satisfaction • Training • Acceptance and support from health authorities, cancer centres, and physicians
Resource Utilization	Objective/Behaviour	Objective/Behaviour
<ul style="list-style-type: none"> • Wait time, e.g., from surgery to follow-up therapy (Develop targets) • Emergency visits • Outpatient clinic visits • Acute care admissions • Oncologist and other specialist visits • Phone calls to professionals (number & nature of call) • Use of psychosocial and other resources, e.g., Patient and Family Counselling, Nutrition Services and Physiotherapy Programs • Calls to Canadian Cancer Society 	<ul style="list-style-type: none"> • Access to Navigator • Knowledge/education • Means of accessing knowledge • Problem solving skills • Social network, e.g. size, type, amount of access, utilization • Preparedness for meetings with specialists • Adherence to treatment/care program • Information acquired at chemo-teaching session(s) • Use of complementary/alternative medicine (CAM) • Medical morbidity • Complaints 	<ul style="list-style-type: none"> • Time allocation for each patient • Referrals obtained, including source of referral • Referrals made, e.g. to nutrition services • Type of activities, e.g.: <ul style="list-style-type: none"> ◊ Facilitating access to care and coordination of services ◊ Informing community about Navigation services ◊ Providing information and support ◊ Preparing patients for visits with specialists ◊ Linking community resources with cancer centres ◊ Facilitating follow-up after treatment ◊ Identifying issues and barriers

Measures and tools

The project team developed several instruments to operationalize the notion of 'Patient Preparedness' and to measure outcomes that were of practical and theoretical significance. In addition, an assessment tool was developed.

Patient Preparedness Questionnaires

The team focused on a small subset of outcomes for which to develop and field test instruments. The following were identified as key outcomes:

- anxiety and distress
- self-efficacy
- preparedness for consultation with specialists
- health-resource utilization
- satisfaction with care
- satisfaction with Navigation services
- surgeons and oncologists perceptions of patient preparedness.

The decision was made to use validated instruments where possible. The project team conducted a literature search, and selected the following three scales as the core measures of Patient Preparedness Questionnaires:

- Level of distress scale: Cognitive Somatic Anxiety Questionnaire ⁽⁴⁷⁾ (14 items)
- Worry Interference Scale ⁽⁴⁸⁾ (7 items)
- Self-efficacy to perform self-management behaviours: Self Efficacy ⁽³⁷⁾ (19 items for Time 1 & Time 2, and 24 items for Time 3)

The team also developed a questionnaire for surgeons and oncologists to rate the degree to which patients were prepared for the consultation.

Patient Preparedness Questionnaire - T1

(Appendix 2), the first patient questionnaire, measured the baseline level of patients' anxiety, interfering thoughts, and self-efficacy, and also included an additional section for demographic data: items on sex, age, marital status, ethnicity, education, and occupation. Ethnicity was included because research indicates that utilization of health services may be different among various ethnic groups.^(31,48,49,50)

Patient Preparedness Questionnaire - T2

(Appendix 3), measured the above outcomes, as well as patient preparedness. The literature search did not turn up any scales on patient preparedness. Domain-relevant experts created the items based on a senior oncologist's description of a well-prepared patient attending a consultation.⁽⁵²⁾ Further input about the items was obtained from several more oncologists and surgeons in BCCA as a means of validating the approach.

Patient preparedness comprised two dimensions: knowledge readiness, and emotional readiness. The items specifically measure: 1) a patient's apparent understanding of the purpose of the consultation and the nature of treatment decisions that need to be made; and 2) readiness to receive expert information and participate in the consultation.

Patient Preparedness Questionnaire - T3

(Appendix 4), contained the core and two additional measures: Health resource utilization (5 items), and patient satisfaction (17 items). Patient satisfaction incorporated five dimensions: access, respect for patient preferences, information and education, emotional support, and coordination and continuity of care. These items were adapted from an ambulatory care patient interview.⁽⁵³⁾

All questionnaires were sent to members of the VIHA Navigation Steering Committee, and the Director of Community Care in the KB for review. Before finalizing the instruments, the patient questionnaire items were further pilot-tested with seven cancer patients. This was *a)* to ensure that the questions were easy to understand; *b)* to identify specific questions that might cause patient discomfort; and *c)* to obtain any other feedback from a patient's perspective. Four patients were recruited from the Patient and Family Counselling program of BCCA's Vancouver Cancer Centre, and three were patients of the VIHA Navigator. All had had surgery two or three months previously, and were either undergoing adjuvant treatment or recovering.

All patients who were involved in the pilot-testing of the questionnaire provided very positive feedback, making comments such as *"This kind of survey is good; it straightens out things"*; and *"The scales are bang on."* These patients appeared particularly to welcome the open-

ended questions in Patient Preparedness Questionnaire T3. Based on their suggestions, some minor wording changes were made.

Patient Identification of Needs (PIN)

To assist the Navigator in creating an individually-tailored intervention and to collect data on patient needs systematically, the project team developed a needs-assessment grid. It was initially drafted based on cancer patients' needs identified in the literature,^(32,49) with categories of needs, such as psychological needs, practical support needs, on the vertical axis; and sources of support, such as family and friends, community resources, and health professionals, on the horizontal axis.

Navigators in the two programs were asked to field test the PIN. Based on their feedback, the team made revisions to improve the efficiency of use and accuracy of descriptions regarding navigator functions. The team also made changes based on what was learned about the changing needs of patients in different stages of the cancer trajectory.

The PIN instrument now enables seven types of needs to be identified and recorded at each stage of treatment (pre surgery, post surgery, pre-oncology visit, and during adjuvant treatment). The seven patient needs are:

- 1) psychosocial support
- 2) help with understanding medical information
- 3) help in communicating with others
- 4) help with decision making
- 5) practical support
- 6) help in maintaining quality of life, and coping with death
- 7) help needed by family members.

Codes for ten intervention types are also provided, to enable Navigators to record the actions they take to address needs. Examples of interventions are:

- 1) Providing direct expert information
- 2) Providing counselling – emotional
- 3) Providing counselling – problem solving.

The complete Patient Needs Identification tool is shown in *Appendix 5*.

Health Care Professional Questionnaire (HCPO) (*Appendix 6*) was developed to as a self-report measure to capture surgeons' perceptions of a patient's level of informational and emotional preparedness for the consultation. The questionnaire is brief and completed by the surgeon after the patient consultation.

3.2 Pilot Testing Instruments & Feasibility of Design

Of the Navigation programs examined, few have *a priori* evaluation plans for either implementation, or continuing effectiveness. Exceptions were the Navigation programs in Nova Scotia and Quebec.⁽⁶⁾ Furthermore, virtually none of the evaluation plans involve a standard experimental or quasi-experimental design.

The team was interested the feasibility of a prospective controlled design, which could potentially produce the strongest method for testing effectiveness. Thus the project team conducted a small study in the 2 sites, to 1) pilot the questionnaires, and 2) test the feasibility of using a quasi-experimental evaluation design.

The objective of the feasibility study was to answer a number of methodological, operational and program questions sufficient to provide the basis for the design of a larger regional survey, and for planning future evaluation studies.

In addition, the goal was to determine whether the questionnaires developed were acceptable in terms of length, ease of understanding, and timeliness. Given the short period available for running this pilot (3-4 months), a test of the effectiveness of the Navigation interventions was not conducted.

In general, the methodology consisted of selecting a sample of patients after the diagnosis of cancer was confirmed and before consultation with surgeon or other oncology specialist. The time window was selected because it is known to be critical, when patients

are at highest risk of experiencing distress, and when the Patient Navigator may have the most beneficial impact. Thus an intervention aimed at providing pre-emptive emotional and educational support should target this pre-consultation time. The target number of patients to be recruited from both sites was 20.

Vancouver Island study: design and patient sample

In VIHA, the first telephone interviews were to be conducted within one week of referral to a surgeon (T1), the second interview after the consultation with the surgeon but before surgery (T2), and the last after surgery (T3). Copies of the Health Care Professional Questionnaire (*Appendix 6*) were sent to surgeons to assess the preparedness of patients who were in the study. The quasi-experimental design is illustrated in *Figure 1*.

Patient Sample

To implement the study design, the project team identified two groups of breast cancer patients. Patients in the Intervention Group were cared for

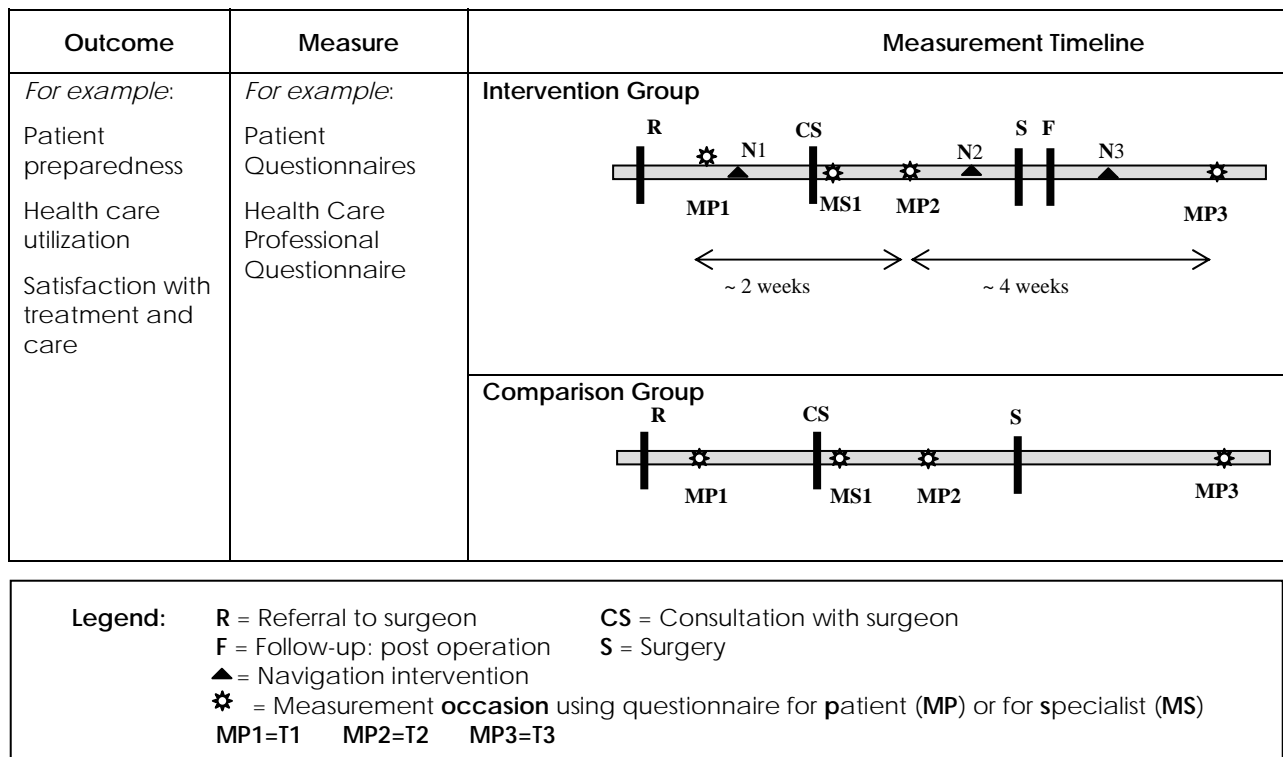
in the Victoria area where the service of the Navigator was available. Patients in the Comparison Group received their care in the Nanaimo and Duncan geographical areas, approximately 60 miles from Victoria, where there was no Navigator available.

Patients in both groups had to meet the following criteria:

- received first primary diagnosis of breast cancer;
- had not yet had surgery;
- older than 19 years of age, and English-speaking.

The study on Vancouver Island began in November 2003, applying the evaluation design as devised.

Figure 1. The VIHA Quasi-Experimental Design



Kootenay Boundary study: design and patient sample

In the Kootenay Boundary region, cancer patients could be men or women who are diagnosed with any form of cancer. Some patients received surgery before radiation or chemotherapy treatment, whereas others received radiation or chemotherapy treatment before surgery.

In the KB region, patients were to be interviewed within one week after consultation with their surgeons (T1), within a week after consultation with their oncologists (T2), and a week after completion of radiation and/or chemotherapy treatment (T3). The study design is shown in *Figure 2*.

The patients' oncologists completed the Health Care Professional Questionnaire (*Appendix 6*) to assess their preparedness for the consultation visit.

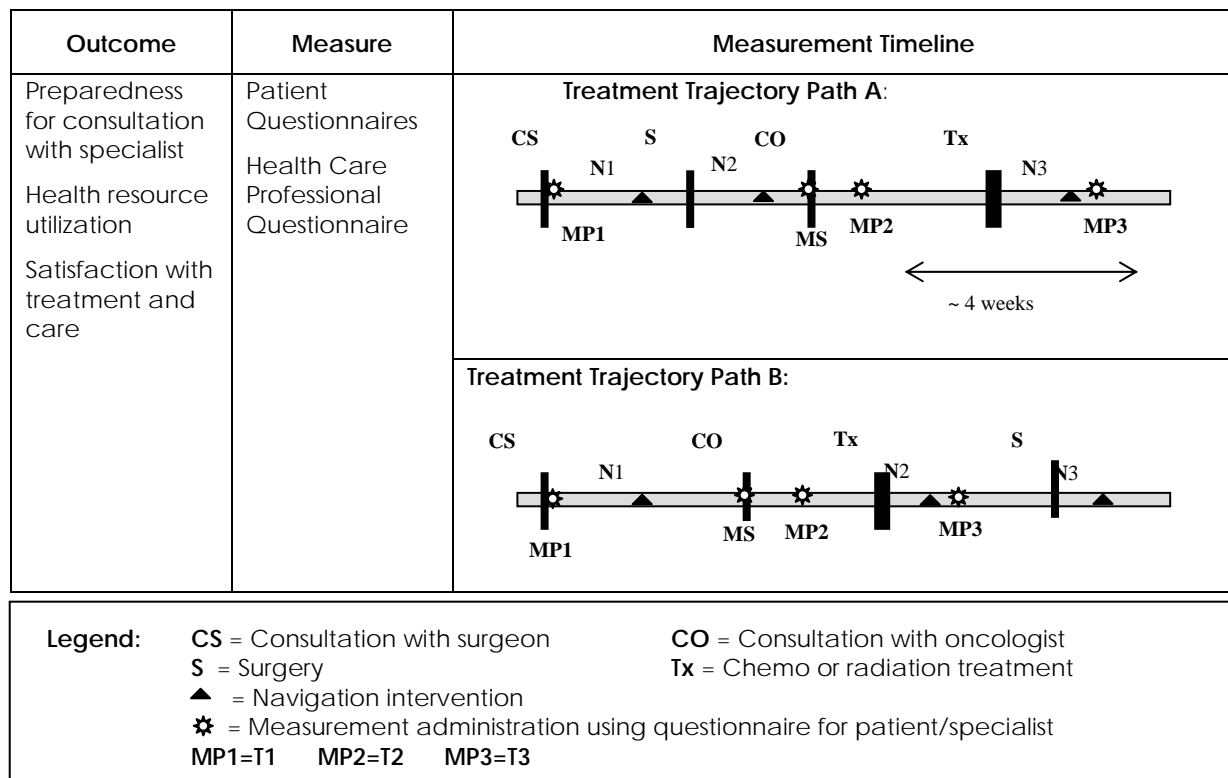
Patient Sample

Patients were recruited from those who saw surgeons in the Kootenay Regional Hospital, and who were provided with an information and consent package (*Appendix 7A-D*). Patients who responded had to meet the following selection criteria:

- recently diagnosed with cancer;
- had not yet had treatment;
- older than 19 years of age, and English-speaking.

The study began in the Kootenay Boundary region in January 2004, and ended in March 2004.

Figure 2. Kootenay Boundary study design



Results from two test sites

Demographic characteristics

The sample population of this pilot, which included patient from VIHA and KB, had over-representation of married women with children (84.6%). The respondents' age range was from 40 to 87 years old, with an average age of 57 years old. About one third of the women were working, and another third were retired.

Patient Preparedness Questionnaire (PPQ) T1, T2 and T3

This questionnaire was intended to capture a number of outcomes related to patient informational and emotional preparedness. In the study, it was used as an interview at specific intervals.

Response rate

In Victoria, a total of 20 patients were eligible to participate (*Table 2*). Of this total, 13 patients completed the questionnaires, resulting in a response rate of 65%. Four patients withdrew early because they reported feeling overwhelmed by the news of their diagnosis. Five patients were approached but did not meet the entry criteria, and were not eligible for the study (1 had limited English-proficiency, 1 had a previous cancer, and 3 were referred after consultation with specialist). Two patients (10%) refused to participate, citing lack of interest.

Table 2. Vancouver Island response rate

	Number	Percentage
Response rate	13	65 %
Refusal rate	2	10 %
Early withdraw/ no contact	5	25 %
Total	20	100%

In KB, 12 patients met the criteria for inclusion and only two were not eligible. The response rate (33%) was lower than in Victoria (*Table 3*).

Table 3. Kootenay Boundary response rate

	Number	Percentage
Response rate	4	33 %
Refusal rate	4	33 %
Early withdraw/ no contact	4	33 %
Total	12	100% *

* Rounded Figure

Time to complete, & length of questionnaire

Time to complete was reported by patients to be acceptable. The average time for completion of PPQ T1 and T2 was 24 minutes. The minimum and maximum times reported were 15 and 35 minutes respectively.

Time to complete PPQ T3 was on average 38 minutes, ranging from 25 to 65 minutes.

Ease of understanding

Comprehension was judged to be good, since all questions were answered by participants without reported difficulty.

Health-care Professional Questionnaires

This questionnaire was intended to capture surgeons' perceptions of patients' level of informational and emotional preparedness for the consultation. It is a brief questionnaire completed by the surgeon after the consultation.

Response rate

Thirteen HCPQs were completed in total, all by surgeons in Victoria. This resulted in a 100 % response rate. Only two HCPQs were completed by oncologists in KB region, representing a very poor response rate.

Time to complete/length of questionnaire

The questionnaire took about 3 minutes to complete.

With the caveat of the small number of responses, it is noteworthy that, overall, there

was a similar rating of preparedness between what the physicians said about patient preparedness, and what patients themselves reported.

Patient Identification of Needs (PIN)

The VIHA and KB navigators used the PIN with a total of eleven patients during the pilot study. The patients who were seen four times were seen during all four phases identified by the team as most critical with regard to support: pre-surgery, post-surgery, pre-oncology visit, and during adjuvant treatment. During each navigator visit, patients could indicate multiple needs at one time; which the results in *Figures 3-6* demonstrate.

The first navigation session, the pre surgical consultation, was always the longest ranging in duration, ranging from 15 to 135 minutes, depending upon the needs of the patient. The average duration of this first session was 60 minutes. Needs most often arising that require navigator intervention were: psychosocial support; help with understanding medical information; help in communicating with others; help with decision-making; and practical support.

Figure 3. Patient-Identified Need: psychosocial support

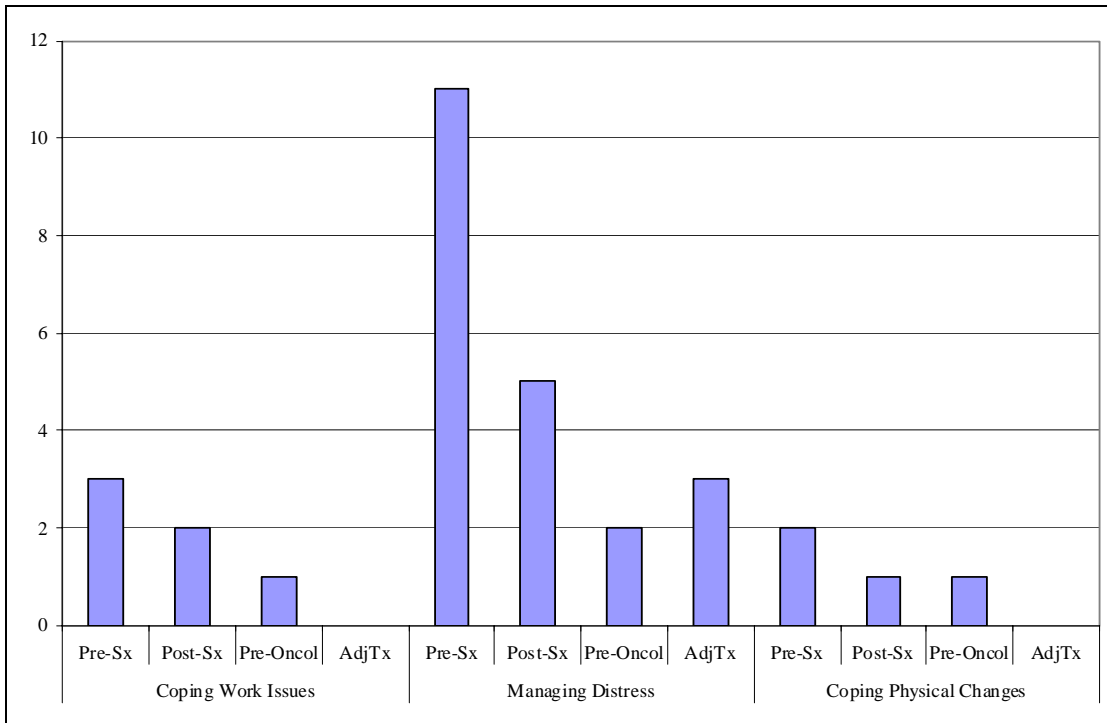


Figure 4. Patient-Identified Need: information

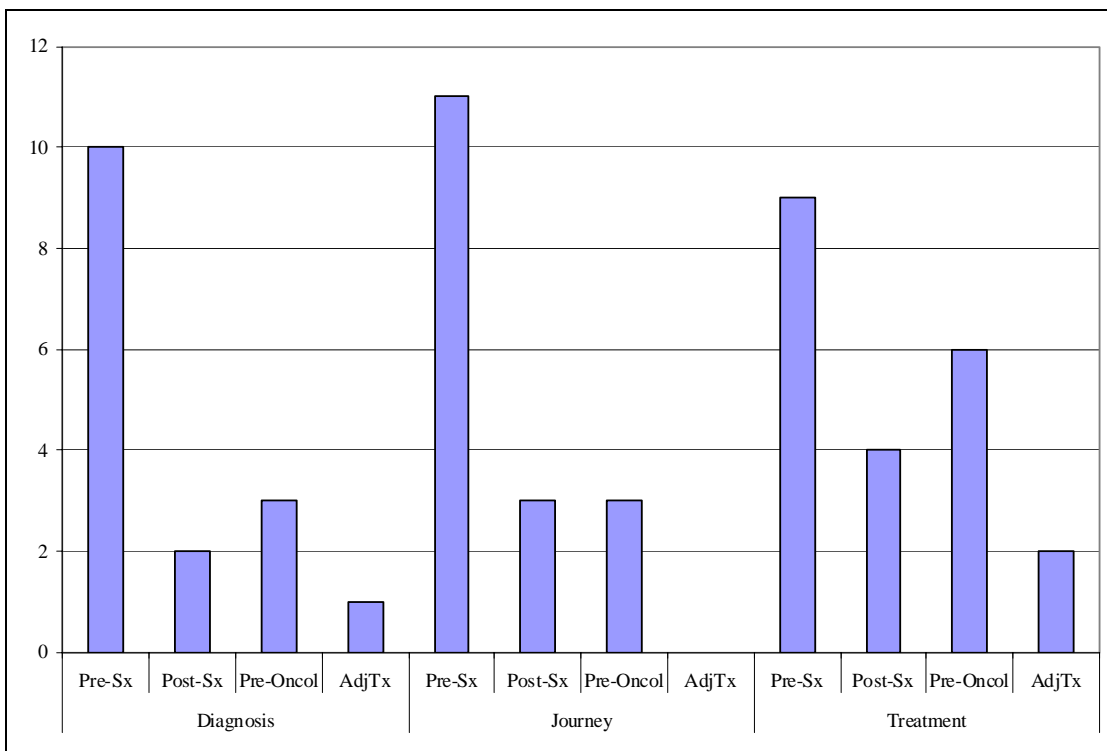


Figure 5. Patient-Identified Need: assistance with communication

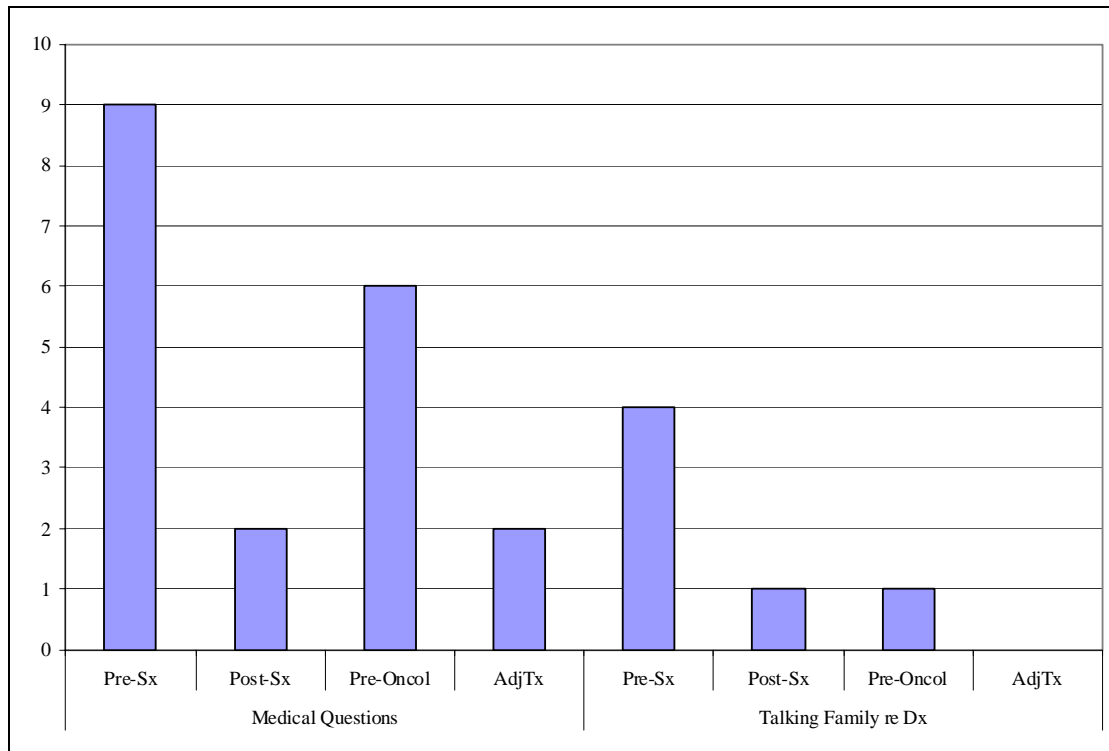
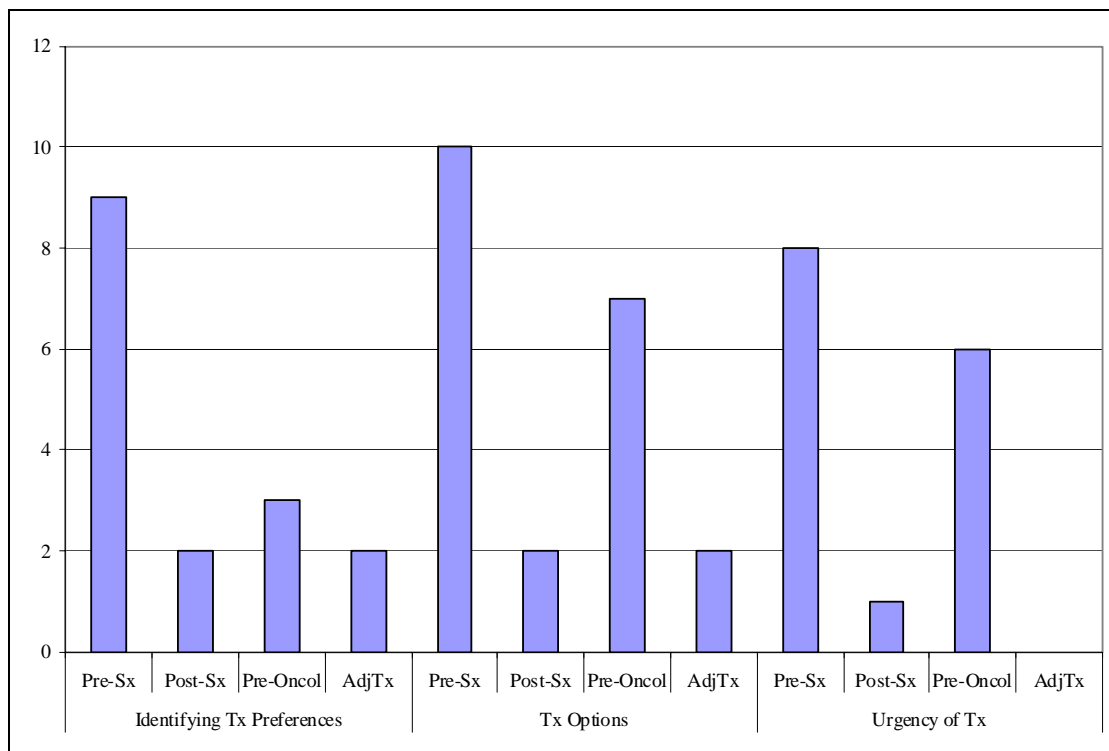


Figure 6. Patient-Identified Need: assistance with decision-making



Challenges to implementing the design

Challenges to implementing the design were posed primarily by issues in coordination, integration and continuity within the different layers of health providers, and a shortage of time to conduct the pilot work.

Recruitment was more difficult than expected, particularly in the KB region. One reason was the short time-window between family physician referral and surgical appointment. In many cases the time interval between confirmed diagnosis and surgical consultation was short: often two or three days, and at most two weeks, often spanning a weekend. On the other hand, completing the necessary tasks of mailing study packages, obtaining consent, and referring the intervention group patients to the Navigator, required at least seven or eight days.

Another reason for low recruitment was timing. Many of the patients who decided not to participate in the study reported being overwhelmed and distressed by their recent diagnosis. They reported not wanting anything else to think about. As a result, it may be that the patients with a lower level of distress were over-represented in this sample. It also suggests that if this problematic aspect of recruiting research-study patients is representative, the clinically-desirable goal of early intervention may be more difficult to achieve.

Lastly, family doctors were not considered in the design of the study, although they are the first patient contact. In future work, it will be imperative to increase awareness of the program among family physicians and the community in general, so that patients are either referred by their primary-care providers, or they can self-refer to the Navigator. This strategy will also offer the benefit of educational and emotional support prior to confirmed diagnosis.

Examination and discussion of the role of family physicians is reported in section 3.3.

Conclusion

The data presented here must be viewed with caution, since the pilot sample does not allow

for strong conclusions. More studies are needed to test these questionnaires at a larger scale and with a controlled design.

Nevertheless, despite the small sample, the findings from the feasibility study are encouraging.

Positive results of the feasibility testing:

- 1) The questionnaires had good acceptability, were easy to understand and required short time for completion;
- 2) the response rates were good;
- 3) these tools can be used for future studies to test reliability and validity.

In summary, despite the differences in the Navigation programs and the backgrounds of the Navigators, both Navigators spent a similar amount of time with patients and provided similar services.

In both programs, patient-needs most often identified were: psychosocial support, help with understanding medical information, help communicating with others, and practical support. The needs were more critical in the pre-surgery consultation.

Although the purpose was not to conduct an evaluation study, some data relevant to program evaluation were gathered. Overall, both health professionals and cancer patients were satisfied with Navigation services in the VIHA and KB regions. When the team piloted the questionnaires with patients who had seen the Navigator in the VIHA, their comments about her work were all positive:

"The Navigator is patient, supportive, and helpful"

"She is a great listener and is accepting"

"She is a wealth of knowledge"

"She helped me know what would happen in the next steps"

"She helped me come to conclusions and find solutions".

Similarly, the cancer patients in the study found their respective Navigators to be of great assistance. They appreciated getting specific information, for example, on lymph-node drainage, prostheses, and the meaning of their pathology reports. They reported valuing the Navigators as non-judgemental, prompt in returning calls, good listeners, and not rushed for time. Two quotations from patients describe what they found useful:

"She was great with everything....She was really supportive, she understood how I felt about losing a breast. Losing as much as you do, you need support there. I was afraid to take off the bandage. That's the scary part, seeing afterwards. ...Explaining and understanding and getting help, where to go for help. In the beginning, it's very hard..." (13).

"...Would have been great if she had been available when my husband had cancer. ...She can help you with what questions to ask, what happens next, can tell you to take someone with you, to take notes because you're upset, another piece of bad news... You don't take it all in, you don't remember much..." (05).

In the KB region, members of the Cancer Care Navigator Advisory Committee were interviewed about the Navigation program. When asked if their community's capacity to look after patients had increased since there was a Navigator in the region, they stated: *"Definitely – there are more options, programs and activities. Patients are getting what they want and need"*.

The committee gave two reasons why the Navigator was so successful in getting programs implemented:

- 1) The projects she developed are community-partnered, and developed so that everyone is aware of the needs of patients and everyone is participating with patient needs in mind. Cancer patients are driving the committees.
- 2) The Navigator approaches family physicians in a way that encourages their positive responses. She meets with doctors during rounds, "a key place" and relates briefly and simply, telling them what she can do and what she needs from them. She explains what a

psychosocial empowerment model is, and why it is beneficial to patients. She also describes what the group programs are, and what they are meant to achieve. In this way, other health professionals reported that the Navigator had made a "significant impact" in the community.

3.3 The Role of the Family Physician in Patient Navigation

As part of the consultation process with other health care professionals, the team learned that many family physicians consider themselves as fulfilling a Navigator function. Family physicians are the pivotal community health-care providers for their patients. They coordinate care, and are the constant presence in a sometimes bewildering array of professionals providing patient care. Due to a number of factors, including lack of educational supports, patient volume, and the complexity of cancer care, many doctors cannot provide all the Navigation functions that their patients may find beneficial.

The national commitment to primary health-care renewal and the continuing emphasis on providing care closer to home has heightened the need to improve coordination and linkages between tertiary-care providers and their community counterparts.

Family physicians represent the access-point for patients and their families needing cancer care, and the role of the family physician can be enhanced and supported by the patient Navigator role.

The team realized that it would be important to develop a better understanding of the physician perspective on Navigation. Moreover, the challenges experienced in the current study in recruiting patients early after diagnosis reinforced the important role that the family physician could play in helping patients access a Navigator.

Therefore, family physicians were sampled to obtain an understanding of their perspectives on, and preferences about, the Navigator

role, including how they would like to work with Navigators.

Method

The research team adapted a measure, the *European Society of Medical Oncology Supportive/Palliative Care Survey* ⁽⁵⁴⁾ for use with family physicians on the topic of patient Navigation.

The final version of the Family Physician Questionnaire (*Appendix 8*) was emailed and faxed to reach family physicians, in three geographical areas of BC: northern, south central and lower mainland. The physician contacts were selected because they had interest in Patient Navigation, were willing to distribute the questionnaire to family physicians in their areas, and because their different locations could provide a range of responses to the questions.

These physician contacts were asked to forward the questionnaire, along with a covering letter, to their colleagues. In the covering letter, those additional doctors were asked to indicate whether they would prefer to be interviewed, or whether they would prefer to return the completed questionnaire to the assistants.

It was estimated that filling out the questionnaires would take 10 minutes and that an interview would take 20 minutes. The physician contacts would then inform the team of their interview request, or would fax the completed questionnaires to the coordinator. If the physician chose to be interviewed, the coordinator or researcher would follow up and arrange an interview. An honorarium of fifty dollars was offered to physicians for their time.

Results

Sixteen questionnaires were returned by family physicians practising in the Kootenays and northern BC. Filling out the questionnaires at their own time was preferred, with no physician choosing to be interviewed.

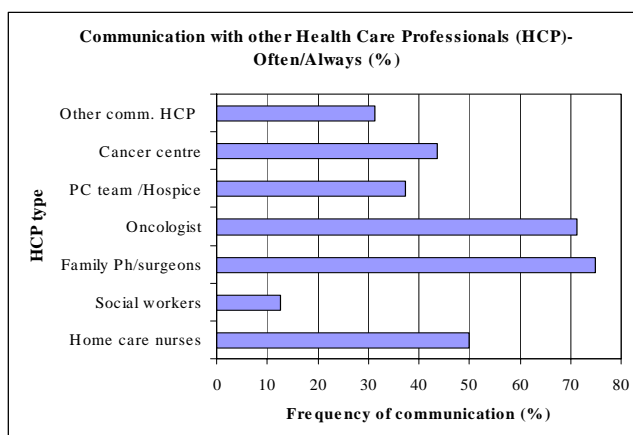
Demographics characteristics

The ratio male to female among respondent was 2 to 1. The average age of the physicians was 43 years, and they had on average 16 years of experience in family practice. Ten family physicians (63%) were not aware of a Patient Navigator in their areas.

Highlights of pilot survey

Despite the small number of respondents, the pilot data is suggestive of some patterns in relation to family-physician involvement in coordination of care and Navigation role. For instance, when asked about the frequency of contact with other health professionals to discuss cancer care, physicians reported having frequent communication with other family physicians or surgeons, oncologists, and home-care nurses. On the other hand, they occasionally or never communicated with social workers, or other community health-care personnel, such as physiotherapists or occupational therapists. About 50% responded that they occasionally communicated with a palliative care team or hospice. Results are summarised in *Figure 7*.

Figure 7. Family Physician Navigation



In general, family physicians reported to be frequently involved in providing Navigation services for their patients (*Table 4*).

Table 4. Frequency of selected Navigation activities

Navigation activity	Often/ Always
Explains the details of the diagnosis	93.7
Discusses care preferences with patients	87.4
Discusses emotional impact of cancer	81.2

However, most physicians reported that coordination of meetings with family members or other health professionals, or referring patients to the Cancer Society were activities they rarely perform.

Family physician needs and preferences

Most physicians reported that they would need more time, ready access to information, and enhanced training to become more involved with patient care. *Table 5* illustrates the needs identified.

Table 5. Physician requirements for increased Navigation

Resources	% responses *
More time	75 %
Ready access to information and resources	75 %
Enhanced oncology training	69 %
Appropriate financial incentive/compensation	44 %
Enhanced training in providing emotional support	38 %
More integration with the community cancer team	38 %

** Multiple resources were selected by each respondent*

Most physicians (75%), would prefer to share Navigation functions with a cancer patient Navigator. 18.7% said they would prefer to delegate, and only 6.5% preferred to coordinate care themselves.

One physician added:

"I would prefer if the patient Navigator is a resource person for me to discuss a patient situation with, and between us we decide what services and resources the patient will benefit from - (mainly so that I can stay in the loop and know what is available).

In summary, these data indicate that the majority of physicians sampled do currently engage in some Navigator functions, but would value additional support of a cancer Navigator.

Perceived barriers to doing more are insufficient time, and lack of easy access to needed information and resources.

The findings support the importance of the general practitioner's role, and indicate that family practitioners would prefer to share Navigation responsibilities with other professional Navigators.

To reiterate however, these findings represent a small sample of doctors, and may not be generally representative.

4 DISCUSSION

4.1 Approaches to Patient Navigation

A Patient Navigator is most generally understood to be someone who expedites patient access to services and resources, thereby improving continuity and co-ordination of care. Previous research identified that Navigation work tended to fall into one of three models: an Active Co-ordination Model; a Facilitative Model, and a Shared or Tacit model.

An objective of the present study was to clarify a 'facilitative' Navigator model that addressed both psychosocial needs of patients as well as the perspective of service-providers and the health system.

Quantitative data collected during the feasibility phase of work were not intended to address the model's effectiveness. However the research process provided an opportunity to reflect on whether the model was plausible; whether theoretical constructs and the conceptual model might be enacted in clinical practice; and whether with further work Navigators could realize the principles identified in this study.

Research and theory in the areas of social support, readiness for change, coping and self-efficacy were seen as contributing to defining the work of a professional Navigator. Each of these constructs supports the notion of '*patient preparedness*'. The constructs frame the practices of the Navigators, and provide a theoretical framework within which to inform future Navigation work. A theoretically-driven intervention resting on a strong research base provides the secure foundation for systematic Navigation practice.

By providing a supportive context and listening ear, by providing appropriately-paced information relevant to the patient's immediate situation, and by helping the patient identify gaps in necessary information and support, the Navigators observed in this study facilitated 'patient preparedness'.

'Preparedness' is conceptualised as a 'readiness to engage in active coping'.

At the time of early diagnosis, preparedness might lead to a medical decision and practical preparations for the circumstances of post-surgery. After treatment, preparedness might involve finding a supportive community to help ease transition back to work and discovery of a new normality.

Both Navigators encouraged patients to use coping strategies that have worked for them in the past, offered additional strategies, and helped patients connect themselves to local resources and supports.

Navigators aided patients in becoming more efficacious: to experience a greater sense of control, to be able to make informed decisions, and to care for themselves.

Thus these constructs were highly salient to the work of the Navigators, and provided a meaningful theoretical framework for clarifying the intended outcomes and scope of the intervention.

Both Navigators were able to provide information and support as well as expedite patient access to resources. Differences in their approaches primarily reflected specific patient needs, and availability of local health services.

For instance, the nurse Navigator developed a highly-focused intervention, targeting information and support needs of women with a recent diagnosis of breast cancer. As a breast health nurse working in an urban setting with many resources at hand, a large portion of her

work was providing specific information that her patients needed at a high-stress time. She was able to interpret the significance of test results and discuss these with patients in an unhurried setting; and able to talk through the likely impact and consequences of various possible decisions. If the patient needed more emotional support, the Navigator could refer her to professional counsellors at the local Cancer Centre, or to various community support groups. Thus this Navigator created a highly supportive environment within which to provide expert information to patients. She also provided supportive messages, reinforcing individual empowerment.

The KB Navigator, a social worker by training, had a contrasting population to serve and different health system and resources to support her work. Because she served all cancer patients, she could not be an expert in providing medical information. Instead, she engaged patients in discussion that elicited the gaps in information, and then assisted patients identify where information needs could be met. She showed patients how to access information through the Cancer Agency website, and provided videos and pamphlets. She also coached patients on how to get information when doctors were perceived to be too busy. Thus, she provided for patient information needs in more indirect and facilitative ways, and not as an expert.

In the rural health region of her practice, there were few emotional resources for patients. Recognizing that she could not reach the entire region, she adopted a community development approach and helped build capacity for providing emotional resources: a 'train the trainer' model which led to local expertise in facilitating support groups for cancer patients; identifying community partners to finance a Dragon Boat team; and linking with other health professionals to create resources such as a Caregiver Information and Support Group, and a Cancer Care Fitness Program.

Both Navigators fulfilled the function not only of increasing access and integration of health care services, but also of providing information and support both directly and indirectly.

These are the essential characteristics of a facilitative Navigator model, and the ability of the Navigators to enact them flexibly demonstrates the model's strength.

A conclusion of this study is that Navigation should not be approached too narrowly or rigidly.

Navigation work differs in diverse settings, and can be enacted by different professionals.

Navigators will differ in how they provide emotional and informational support, reflecting their professional training, their patient population, and the specific health system context in which they operate.

Such flexible enactment should enable regional Health Authorities to appoint Navigators on the basis of local needs and personnel. It should also enable Navigators to develop their practice on the basis of needs, gaps, and their particular skills. Navigation should in all cases be systematic.

The following core characteristics are recommended to structure future Navigation interventions:

- 1) Intervention should be time limited and targeted to high risk phases and service delivery gaps.
- 2) Patient needs for information, support and practical help should be assessed.
- 3) Intervention should have the goal of 'patient preparedness'.
- 4) Information should be paced.
- 5) Intervention should be supportive, but not psychotherapeutic.

In conclusion, a singular model of Navigation is not recommended, but Navigation work will be enhanced if the above features are explicitly developed and integrated into Navigation programs.

4.2 Research on Patient Navigation

The team were able to identify clinically and theoretically relevant outcomes, and to

develop measures that are acceptable to patients, composed mostly of already-validated measures with known validities, which are relevant to the psychosocial challenges of cancer patients.

The Patient Preparedness measures, in particular, would be useful to other Navigation programs pursuing research. Used as a self-report measure, it could be integrated into Navigator practice, providing a relevant and time-efficient measure both to guide Navigator practice and to provide data for program evaluation.

The Health Professional Patient Preparedness tool is probably less useful in an evaluation context. At this time, its sensitivity is unknown, and having surgeons and oncologists complete this tool presents many practical challenges. The PIN assessment tool needs to be further simplified before being practical for other Navigators. It was not utilized fully by the Navigators in the study, who preferred their own assessment methods, and found the tool cumbersome with regards to the number of coding categories.

However, the PIN is worth further refinement, as it provides an assessment of both patient needs and system resources. Although outside the scope of the current study, training in the use of the PIN appears likely to lead to more effective use, since the PIN should guide Navigators to view each patient systemically, that is, within their own constellation of needs and resources. Thus the PIN, properly used, should direct system-sensitive Navigation practice.

A goal of this study was to collect data using a quasi-experimental method, and this approach did not prove fruitful. Thus while the research team recommend the measures, it is not recommended that others attempt a similar design with regard to timing, interviews, or number of patient contacts.

The same complexities and fragmentation in cancer care which drive the need for Navigation also pose barriers to rigorous research.

Experimental methods are the 'gold standard' for testing effectiveness of interventions, but such approaches require control, established

by securing simplicity, standardization and linearity. By its nature, however, Navigation is systemic and complex, seeking to locate bridges between systems and many spheres of care. These realities of Navigation practice make experimental procedures nearly impossible.

Researchers wishing to study Navigation using experimental methods must focus on a very small piece of the cancer journey and the cancer care system.

It is, reasonable to state that interventions can be evidence-based, to the degree that Navigators: incorporate theoretical constructs into their work; provide information and support that patients identify as needed; and use listening, advising, and reference to existing resources. All these components of Navigation are empirically supported.

5 RECOMMENDATIONS FOR FUTURE WORK

Our work in the examination of patient navigation began in the late 1990's with pilot work conducted in the West Kootenay Boundary Region of British Columbia. In 2001 our involvement with a committee of the Canadian Breast Cancer Foundation (CBCF) helped initiate investigation of patient navigation through the commission of a review of the state of patient navigation in health care. The completion of a report (Farber, Deschamps) determined that patient navigation was not a well used term, with only one published report noted. Descriptions of approaches or models for navigation were not addressed in the literature nor were data available reflecting the evaluation of navigation interventions or programs.

Much has changed since the completion of this report in 2002. An internet scan now reveals dozens of references to patient navigation. In fact the term is used quite regularly by patients, health practitioners and even policy makers. In 2005, the Alberta Cancer Board sanctioned a process to determine what role this provincial agency should take in regards to the development of patient navigation. Also this year, the Provincial Health Services Authority in BC in conjunction with the BC Cancer Agency sponsored a forum geared to providers and policy makers to address the potential application of patient navigation to meet continuing problems of access and continuity of care. Financial support from the Federal Primary Health Care Transition Fund

has initiated the development of project work in patient navigation in several jurisdictions in BC. Funding for navigation programs continue in other provinces.

To move Patient Navigation program development and research forward, the BCCA team initiated a national collaborative effort with an emphasis on implementation and integration of research and clinical practice, and bringing together program-developers, researchers and decision-makers from Nova Scotia, Quebec, Ontario, Alberta and BC. The plan is to identify common models, share assessment tools and education materials, and identify challenges and opportunities for further development of Patient Navigation.

An initial meeting was held in the spring of 2005 under the auspices of the Canadian Strategy for Cancer Control (CSCC), Rebalance Focus Action Group. This group has accepted responsibility to work nationally by encouraging a collaborative effort in advancing work for patient navigation. A national approach is viewed as desirable despite the fact that navigation programs will be developed on a regional or provincial basis. Those interested in patient navigation have identified the importance of using common tools to forge ahead. Considering this approach a number of recommendations are made for future work.

Recommendation 1

It is crucial that Navigation programs are developed in more communities according to the needs of patients, the existing strengths within communities and the financial resources of regional health authorities. Broad directives as to outcome, rather than rigid interpretation of process, will be most useful in ensuring flexible enactment, and best use of resources.

Recommendation 2

One of the criticisms of instituting a professional Navigator role can be understood in the statement: *“rather than creating a role that fixes holes in the system, we should be fixing the system”*. Navigators can be catalysts for system change and should view their role as such. A single focus on patient needs without a broader awareness of possibilities for system change is likely to impede growth and implementation of Navigation approaches. When Navigators function as educators to physicians, as members

of interdisciplinary teams, as community developers, they are adding value to their role and contributing to system change.

Recommendation 3

Navigation programs need stable funding in order to provide ongoing, consistent, and expeditious care to all patients. The longer a Navigator is in the role, the greater is its potential value. Only with time do Navigators develop relationships with physicians and the community, and with providers of care and personnel in health authorities and regions.

Recommendation 4

Health authorities and the cancer centres need to work together, developing a common sense of the shared ownership of the programs. The Navigator should act to strengthen links between primary, tertiary, and Cancer Centre care. By establishing firm connections with family physicians, they facilitate more timely access during the initial diagnosis phase; by developing strong links with local cancer centres, they facilitate reliable access for patients returning to the community for adjuvant treatment or rehabilitation.

Recommendation 5

Navigators should be encouraged to use common patient assessment tools which serve two functions: directing the care plans of individual patients, and compiling a database documenting patient needs and system resources. This database would be available to improve services.

Recommendation 6

The creation of a national team or network should be supported for purposes of insuring communication between provinces and other jurisdictions to promote sharing of model development, approaches, data management and program evaluation in patient navigation. Consideration for funding applications to sustain such a team should be explored. A program of research should be pursued ideally through the development of a national research network.

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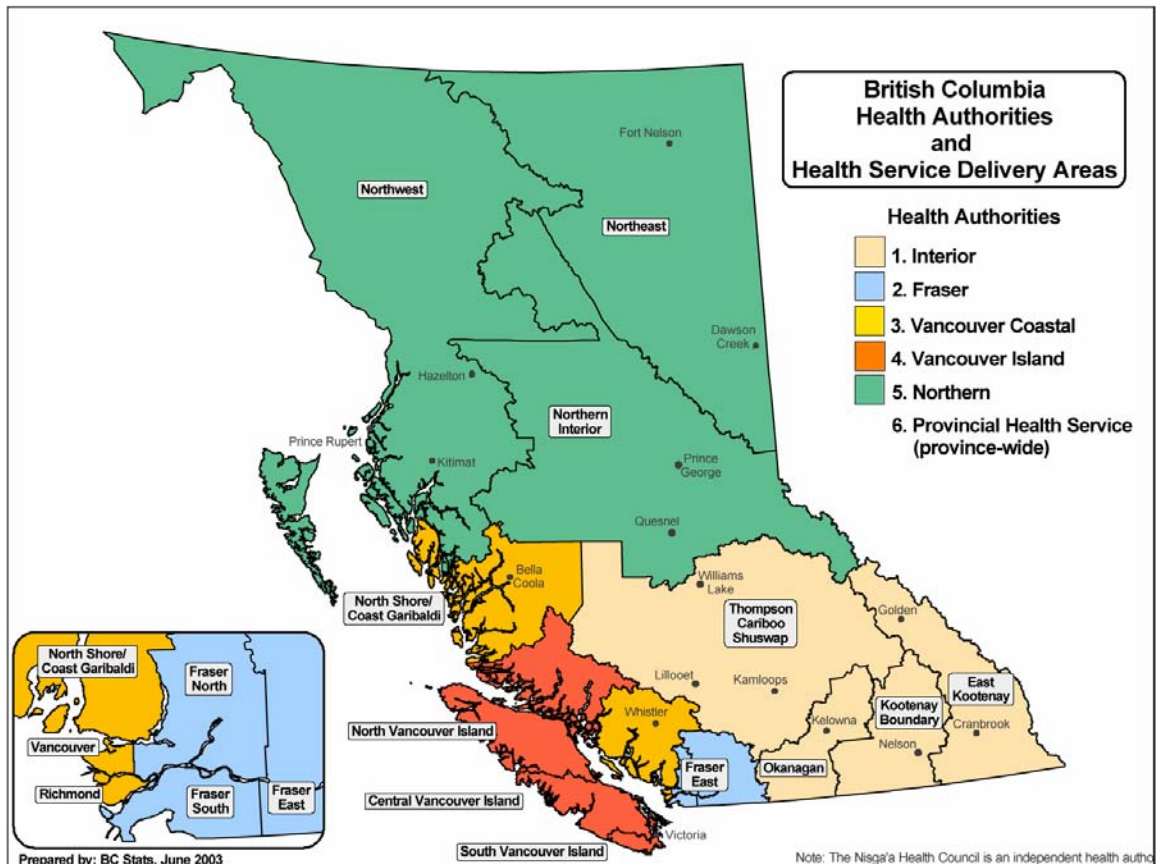
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Appendices

Appendix 1: BC Health Services Map



Appendix 2: Patient Questionnaire – T1



BC Cancer Agency
CARE & RESEARCH

Subject ID							

Patient Preparedness Questionnaire - T1

INTERVIEWER: Introduce yourself, thank patient for taking part in the study, and reassure patient about confidentiality of information. Check if it is a good time to do the interview. If it is, ask patient to have the coloured rating scale sheets in front of her/him and proceed. If not, schedule another time.

Interviewer:

Interview

Start time:

_____ : _____ AM/PM
Hr Min

Interview

Date:

_____/_____/_____
mm dd yy

Signature:

Interview

End Time:

_____ : _____ AM/PM
Hr Min

General Information (INTERVIEWER: Complete Question 1 and proceed.)

"First, I'll ask you several questions about some general background information, which will help us compare the responses of different groups of patients. What is your date of birth?... "

1. Sex of Patient: Female Male

2. What is your date of birth?

____/____/____
mm / dd / yy

3. What is your marital Status? (*Read all options where necessary*)

- Single Married/Common-law/Living with Partner
 Separated/Divorced Widowed

4. Do you have any children? Yes No (Skip to 8.)

5. Number of children _____

6. Age of youngest child _____

7. Age of oldest child _____

8. Do you live alone? Yes No

9. To which ethnic or cultural group do you belong? Are you ... (Read some options as examples and mark all that apply.)

- Aboriginal (e.g., North American Indian, Metis, Inuit)
 Arab/West Asian (e.g., Armenian, Iranian, Lebanese, Moroccan)
 Black (e.g., African, Haitian, Jamaican, Somali)
 Chinese
 Filipino
 Japanese
 Korean
 Latin-American
 South Asian (e.g., East Indian, Pakistani, Sri Lankan)
 South-Eastern Asian (e.g., Cambodian, Indonesian, Laotian, Thai, Vietnamese)
 White (e.g., Caucasian, European)
 Other, please specify _____

Section B: Worry Interference (INTERVIEWER: Do not read out section title.)

"In the next section, I will list ways that thoughts about cancer affect some people. I'd like you to use the scale on the blue sheet and tell me how true each of these items on the list are for you in the past week.

The first item, 'Thoughts of cancer have affected your relationships with others.' Which of these best represents your experience: '1' - 'Not at all', '2' - 'A little', '3' - 'Somewhat', '4' - 'Quite a bit', or '5' - 'A lot'. Just give me the number."

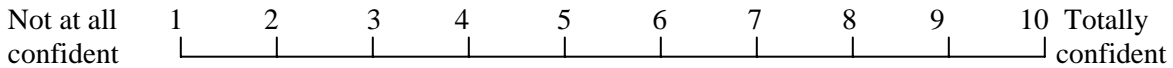
		1 Not at all	2 A little	3 Somewhat	4 Quite a bit	5 A lot
B1.	Thoughts of cancer have affected your relationships with others.					
B2.	Thoughts of cancer have affected your ability to sleep.					
B3.	Thoughts of cancer have affected your work.					
B4.	Concerns about cancer have affected your ability to have fun.					
B5.	Fears of cancer have affected your ability to feel sexually attractive.					
B6.	Worries about cancer have affected your ability to meet the needs of your family.					
B7.	Cancer concerns have affected your ability to concentrate.					

(INTERVIEWER: Please write N.A in the "Not at all" box if subject specifies that the situation is not applicable, e.g., B3. Subject does not work.)

Section C: Self-efficacy (INTERVIEWER: Do not read out section title.)

"In the next section, please use the rating scale on the green sheet. For each question I'll be asking you, please answer how confident you feel at the present time that you can do the task regularly. '1' refers to someone who is 'not at all confident' and '10' refers to someone who is 'totally confident'. Please choose a number between '1' and '10' that best matches how confident you feel about doing the task described in the question.

The first question, 'How confident are you that you can get information about your disease from your health care providers and community resources?' How would you rate your level of confidence between '1' – 'Not at all confident' and '10' – 'Totally confident'... "



INTERVIEWER: Read the question stem each time.

How confident are you that you can ...

- C1. Get information about your disease from your health care providers and community resources? _____
- C2. Get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transport)? _____
- C3. Get emotional support from friends and family (such as listening or talking over your problems)? _____
- C4. Get emotional support from resources other than friends or family, if needed? _____
- C5. Get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed? _____
- C6. Ask your doctor things about your illness that concern you? _____
- C7. Discuss openly with your doctor any personal problems that may be related to your illness? _____
- C8. Work out differences with your doctor when they arise? _____
- C9. Complete your household chores, such as vacuuming and yard work, despite your health problems? _____
- C10. Get your errands done despite your health problems? _____

How confident are you that you can ...

- C11. Get your shopping done despite your health problems? _____
- C12. Continue to do your hobbies and recreation? _____
- C13. Continue to do the things you like to do with friends and family (such as social visits and recreation)? _____
- C14. Keep from getting discouraged when nothing you do seems to make any difference? _____

(INTERVIEWER: If subject sounds unsure about the question or requests repeating the question, phrase it by reading the "when" clause first, i.e., "When nothing you do seems to make any difference, how confident are you that you can keep from getting discouraged?")

C15. Keep from feeling sad or down?

C16. Keep yourself from feeling lonely?

C17. Do something to make yourself feel better when you are feeling lonely?

C18. Do something to make yourself feel better when you are feeling discouraged?

C19. Do something to make yourself feel better when you feel sad or down?

"Thank you very much for your time. I'll be calling you again for the second interview after your visit with your oncologist. Please start using the Medical Visit Log sheet we sent you to document your medical appointments. Do you have any questions about the log sheet? Take good care of yourself."

Appendix 3: Patient Questionnaire – T2



BC Cancer Agency
CARE & RESEARCH

Subject ID							

Patient Preparedness Questionnaire - T2

INTERVIEWER: Greet patient and check if it is a good time to do the interview. If it is, ask patient to have the coloured rating scale sheets in front of her/him and proceed. If not, schedule another time.

Interviewer:	Signature:
Interview Start time: _____ : _____ AM/PM <div style="display: flex; justify-content: space-around; width: 100%;"> Hr Min </div>	Interview End Time: _____ : _____ AM/PM <div style="display: flex; justify-content: space-around; width: 100%;"> Hr Min </div>
Interview Date: _____ / _____ / _____ <div style="display: flex; justify-content: space-around; width: 100%;"> mm dd yy </div>	

Section B: Worry Interference (INTERVIEWER: Do not read out section title.)

"In the next section, I will list ways that thoughts about cancer affect some people. I'd like you to use the scale on the blue sheet and tell me how true each of these items on the list are for you in the past week.

The first item, 'Thoughts of cancer have affected your relationships with others.' Which of these best represents your experience: '1' - 'Not at all', '2' - 'A little', '3' - 'Somewhat', '4' - 'Quite a bit', or '5' - 'A lot'. Just give me the number."

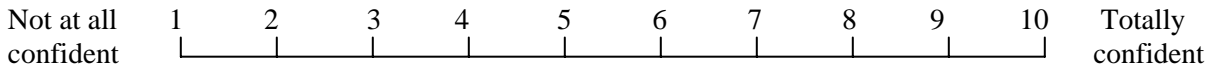
		1 Not at all	2 A little	3 Somewhat	4 Quite a bit	5 A lot
B1.	Thoughts of cancer have affected your relationships with others.					
B2.	Thoughts of cancer have affected your ability to sleep.					
B3.	Thoughts of cancer have affected your work.					
B4.	Concerns about cancer have affected your ability to have fun.					
B5.	Fears of cancer have affected your ability to feel sexually attractive.					
B6.	Worries about cancer have affected your ability to meet the needs of your family.					
B7.	Cancer concerns have affected your ability to concentrate.					

(INTERVIEWER: Please write N.A in the "Not at all" box if subject specifies that the situation is not applicable, e.g., B3. Subject does not work.)

Section C: Self-efficacy (INTERVIEWER: Do not read out section title.)

"In the next section, please use the rating scale on the green sheet. For each question I'll be asking you, please answer how confident you feel at the present time that you can do the task regularly. '1' refers to someone who is 'not at all confident' and '10' refers to someone who is 'totally confident'. Please choose a number between '1' and '10' that best matches how confident you feel about doing the task described in the question.

The first question, 'How confident are you that you can get information about your disease from your health care providers and community resources?' How would you rate your level of confidence between '1' – 'Not at all confident' and '10' – 'Totally confident'... "



INTERVIEWER: Read the question stem each time.

How confident are you that you can ...

- C1. Get information about your disease from your health care providers and community resources? _____
- C2. Get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transport)? _____
- C3. Get emotional support from friends and family (such as listening or talking over your problems)? _____
- C4. Get emotional support from resources other than friends or family, if needed? _____
- C5. Get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed? _____
- C6. Ask your doctor things about your illness that concern you? _____
- C7. Discuss openly with your doctor any personal problems that may be related to your illness? _____
- C8. Work out differences with your doctor when they arise? _____
- C9. Complete your household chores, such as vacuuming and yard work, despite your health problems? _____
- C10. Get your errands done despite your health problems? _____

How confident are you that you can ...

- C11. Get your shopping done despite your health problems? _____
- C12. Continue to do your hobbies and recreation? _____
- C13. Continue to do the things you like to do with friends and family (such as social visits and recreation)? _____

Keep from getting discouraged when nothing you do seems to make any difference? _____

C14. (INTERVIEWER: If subject sounds unsure about the question or requests repeating the question, phrase it by reading the "when" clause first, i.e., "When nothing you do seems to make any difference, how confident are you that you can keep from getting discouraged?") _____

C15. Keep from feeling sad or down? _____

C16. Keep yourself from feeling lonely? _____

C17. Do something to make yourself feel better when you are feeling lonely? _____

C18. Do something to make yourself feel better when you are feeling discouraged? _____

C19. Do something to make yourself feel better when you feel sad or down? _____

Section B: Worry Interference (INTERVIEWER: Do not read out section title.)

"In the next section, I will list ways that thoughts about cancer affect some people. I'd like you to use the scale on the blue sheet and tell me how true each of these items on the list are for you in the past week.

The first item, 'Thoughts of cancer have affected your relationships with others.' Which of these best represents your experience: '1' - 'Not at all', '2' - 'A little', '3' - 'Somewhat', '4' - 'Quite a bit', or '5' - 'A lot'. Just give me the number."

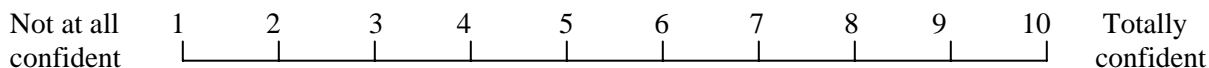
		1 Not at all	2 A little	3 Somewhat	4 Quite a bit	5 A lot
B1.	Thoughts of cancer have affected your relationships with others.					
B2.	Thoughts of cancer have affected your ability to sleep.					
B3.	Thoughts of cancer have affected your work.					
B4.	Concerns about cancer have affected your ability to have fun.					
B5.	Fears of cancer have affected your ability to feel sexually attractive.					
B6.	Worries about cancer have affected your ability to meet the needs of your family.					
B7.	Cancer concerns have affected your ability to concentrate.					

(INTERVIEWER: Please write N.A in the "Not at all" box if subject specifies that the situation is not applicable, e.g., B3. Subject does not work.)

Section C: Self-efficacy (INTERVIEWER: Do not read out section title.)

"In the next section, please use the rating scale on the green sheet. For each question I'll be asking you, please answer how confident you feel at the present time that you can do the task regularly. '1' refers to someone who is 'not at all confident' and '10' refers to someone who is 'totally confident'. Please choose a number between '1' and '10' that best matches how confident you feel about doing the task described in the question.

The first question, 'How confident are you that you can get information about your disease from your health care providers and community resources?' How would you rate your level of confidence between '1' – 'Not at all confident' and '10' – 'Totally confident'..."



INTERVIEWER: Read the question stem each time.

How confident are you that you can ...

- C1. Get information about your disease from your health care providers and community resources? _____
- C2. Get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transport)? _____
- C3. Get emotional support from friends and family (such as listening or talking over your problems)? _____
- C4. Get emotional support from resources other than friends or family, if needed? _____
- C5. Get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed? _____
- C6. Ask your doctor things about your illness that concern you? _____
- C7. Discuss openly with your doctor any personal problems that may be related to your illness? _____
- C8. Work out differences with your doctor when they arise? _____
- C9. Complete your household chores, such as vacuuming and yard work, despite your health problems? _____
- C10. Get your errands done despite your health problems? _____

How confident are you that you can ...

- C11. Get your shopping done despite your health problems? _____
- C12. Continue to do your hobbies and recreation? _____
- C13. Continue to do the things you like to do with friends and family (such as social visits and recreation)? _____

- Keep from getting discouraged when nothing you do seems to make any difference? _____
- C14. (INTERVIEWER: If subject sounds unsure about the question or requests repeating the question, phrase it by reading the "when" clause first, i.e., "When nothing you do seems to make any difference, how confident are you that you can keep from getting discouraged?") _____
- C15. Keep from feeling sad or down? _____
- C16. Keep yourself from feeling lonely? _____
- C17. Do something to make yourself feel better when you are feeling lonely? _____
- C18. Do something to make yourself feel better when you are feeling discouraged? _____
- C19. Do something to make yourself feel better when you feel sad or down? _____
- C20. Reduce your physical discomfort or pain? _____
- C21. Keep the fatigue caused by your disease from interfering with the things you want to do? _____
- C22. Keep the physical discomfort or pain of your disease from interfering with the things you want to do? _____
- C23. Keep any other symptoms or health problems you have from interfering with the things you want to do? _____
- C24. Control any symptoms or health problems you have so that they don't interfere with the things you want to do? _____

Section D: Health Care Utilization

"In the next section, I will ask you questions about the health services you used in the past 2 months..."

- D1. Have you had a surgery to remove your cancer? Yes No
 If 'Yes', how many days did you stay in the hospital for the surgery?
 _____ days
- D2. Not counting your surgery stay, how many nights did you stay in a hospital in the past 2 months?
 None _____ Nights
 Reasons for stay: _____
- D3. During the past 2 months, how many times, if any, did you go to see the following? I'll read you a list of health care providers. Please say how many visits you had with each one. Do not include visits while you were in the hospital. Refer to your medical visit log if necessary.

	# of Visits
Family doctor/GP or walk-in clinic	_____
A surgeon	_____
Any other cancer specialist: a medical oncologist or radiologist	_____
A counsellor/Psychologist	_____
A chemo nurse	_____
A physiotherapist	_____
A health professional in the X-ray department	_____
Cancer Care Navigator	_____
Practitioner of alternative/complementary medicine	_____
A home health nurse	_____
Support group	_____
Other : (Specify)	_____

INTERVIEWER: For D3, please note any comments that subject makes to elaborate answers.

- D4. In the past 2 months how many times did you visit the emergency room?
 None _____ times
 Reasons for emergency room visit(s):

- D5. As far as you know, will you be starting any other treatment?
 None
- | | Scheduled Start Date (mm/dd/yy) |
|---|---------------------------------|
| <input type="checkbox"/> Surgery | _____ |
| <input type="checkbox"/> Chemotherapy | _____ |
| <input type="checkbox"/> Radiation therapy | _____ |
| <input type="checkbox"/> Hormone therapy | _____ |
| <input type="checkbox"/> Other (Please specify) | _____ |

Section E: Patient Satisfaction with Cancer Care

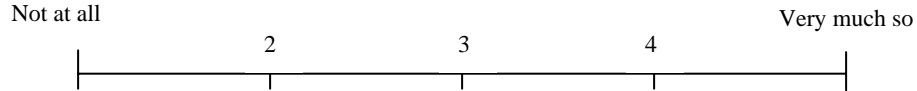
"In the next and last section, I will be asking you what you think about the different aspects of cancer care in the past two months. Use the scale on the pink sheet again. Answer each question by choosing a number between '1' – 'Not at all' – and '5' – 'Very much so' – that best matches your view."

(INTERVIEWER: Record comments on individual questions if subject wants to elaborate her/his assessment or differentiate the various types of health care providers, e.g., family physicians, surgeons, oncologists.)

	Not at all	2	3	4	Very much so	
E1.	Did you get your cancer care appointments in the time you expected to?					_____
E2.	Was it easy to talk to someone and get medical advice or help right away?					_____
E3.	Did your health care provider(s) listen to what you had to say?					_____
E4.	Were you involved in decisions about your care as much as you wanted?					_____
E5.	Did you get as much information about your condition and treatment as you wanted from your health care provider(s)?					_____
E6.	When you asked questions, did you get answers you could understand?					_____
E7.	Were you able to talk about feelings or concerns you had?					_____
E8.	Did you have confidence and trust in your health care provider(s)?					_____
E9.	Did you have a chance to talk about how your family or living situation might affect your health?					_____
E10.	Did your health care provider(s) explain what to do if problems or symptoms continued, got worse, or came back?					_____
E11.	Did you have any follow-up visits that you thought could have been avoided by better coordination?					_____
E12.	Was there a time when you thought your health care providers did not talk to each other enough about your care?					_____
E13.	If you were referred to a specialist, did the specialist have the information he/she needed from your medical records?					_____

"In the following question, I will ask for your overall impression."

E14. Overall, how satisfied were you with your care during the past 2 months. Choose the number between '1' - 'Not at all' satisfied and '5' - 'Very much so' that comes closest to your rating.



E15. Are there any additional comments you would like to make? For example, is there anything in the health care system that could have been done differently to improve your care experience?

E16. What have been the greatest contributions of the Cancer Care Navigator to your cancer care experience? Please describe the most important 2 or 3.

E17. Is there anything that the Cancer Care Navigator could have done to improve your experience of care?

"Thank you very much [name]. We appreciate your time and helpfulness. The information you have given is invaluable to us. Based on input from you and other patients, the research team hopes to find ways of improving patients' experience in cancer care. Would you like to receive a copy of the study report when it is ready? (INTERVIEWER: Record name if subject expresses interest.) Take care and have a speedy recovery."

Appendix 5: Patient Identification of Needs Tool (PIN)

Navigation Study Yes No **Age:** **Diagnosis:**
Patient:
If 'Yes' Patient Name: _____

Based on discussions with your patient:
 (1) Please use a check mark ✓ to indicate the needs where your patient placed a high priority.
 (2) Please use the appropriate intervention legends listed at the end of the table to note how the needs were addressed

Stage				
Need	Pre-Surgical Consult	Post-Surgical Consult	Pre-Oncology Visit	Adjuvant Treatment
Duration (in minutes for contacts)				
Date of first contact for each stage				
(1) Needed Psychological Support				
◆ Managing distress (fear, anxiety, depression)				
◆ Managing change in physical appearance				
◆ Coping with financial issues				
◆ Coping with work issues				
◆ Coping with sexuality issues				
◆ Other psychological/emotional need				
(2) Needed Help Understanding Medical Info about				
◆ Diagnosis				
◆ Tests & exams				
◆ Treatment				
◆ Journey overview				
◆ Future conditions				
◆ Side effects				

Stage Need	Pre-Surgical Consult	Post-Surgical Consult	Pre-Oncology Visit	Adjuvant Treatment
(3) Needed Help Communicating with Others				
◆ Asking questions/ expressing concerns and wants with medical staff				
◆ Talking about disease with family and friends				
◆ Expressing own needs and wants with family and friends				
(4) Needed Help with Decision Making				
◆ Understanding options and impacts				
◆ Understanding urgency of treatment				
◆ Identifying personal preferences				
(5) Needed Practical Support				
◆ Preparing for specialist visits				
◆ Arranging for transportation				
◆ Arranging for financial assistance				
◆ Managing effects of treatment				
◆ Obtaining medical care or home care assistance				
◆ Assistance with daily activities				

Stage Need	Pre-Surgical Consult	Post-Surgical Consult	Pre-Oncology Visit	Adjuvant Treatment
(6) Needed Help Maintaining Quality of Life and Coping with Death				
◆ Controlling disease symptoms				
◆ Dealing with fear and anxiety around death				
◆ Dealing with practical issues around death				
◆ Discussing end-of-life options				
(7) Family Members Needed Help with				
◆ Obtaining and understanding information about disease & treatment				
◆ How to support patient				
◆ Support for self				
◆ Issues about the health care process and advocacy				

Interventions:

- ❶ Provide direct expert information
- ❷ Provide counselling - emotional (Listen, acknowledge, validate, and provide support)
- ❸ Provide counselling - problem solving (Help patients know what they know and do not know, facilitate planning and getting answers)
- ❹ Provide books and information kits
- ❺ Refer to online resources and give internet sites
- ❻ Refer to physicians (family physicians, surgeons, oncologists)
- ❼ Refer to Canadian Cancer Society programs
- ❽ Refer to BCCA/regional hospital services (patient family counselling, nutrition, pain and symptom management, and palliative services)
- ❾ Refer to other community-based supportive care (exercise, physio/chemo, dragon boat team, and hospice programs led by health professionals)
- ❿ Refer to home care nursing

Please complete this questionnaire to provide an assessment of the patient's level of preparedness for the consultation. "Preparedness" refers here to the patient's 1) understanding of the purpose of the consult, 2) readiness to receive expert information, 3) ability to participate actively in the consult, and 4) understanding of the nature of decisions that need to be made.

A. Please indicate "yes" or "no" to each of the following:

- 1. Did your patient bring a family member or a friend into the consultation? Yes No
- 2. Did your patient come with a list of questions related to the consultation? Yes No
- 3. Did your patient and/or family member/friend take notes during the consultation or tape record the discussion? Yes No

B. Based on your best judgement, would you say that your patient:

	1 Very little	2 Somewhat	3 Moderately	4 Very much
4. Knew the purpose of the visit?	1	2	3	4
5. Understood the extent of the disease as known at time of referral, e.g., the size and spread?	1	2	3	4
6. Demonstrated familiarity with the points and issues discussed?	1	2	3	4
7. Demonstrated familiarity with the treatment alternatives you explained and the decision(s) that would have to be made?	1	2	3	4
8. Appeared confused by the information provided?	1	2	3	4
9. Appeared distressed?	1	2	3	4

C. Please indicate, over all, how well your patient was prepared for the consultation.

1	2	3	4
Poorly prepared	Somewhat prepared	Well prepared	Very well prepared

Appendix 7: Feasibility Study Information Package

The study package contents are essentially the same for both feasibility studies. The package materials for the West Kootenay Boundary study are shown here. They include:

- 7A Initial Contact Letter**
- 7B Patient Information and Consent Form**
- 7C Questionnaire Rating Scale Sheets – one sample included**
- 7D Medical Visit Log**



BC Cancer Agency
CARE & RESEARCH



Interior Health

200-601 West Broadway
Vancouver, BC V5Z 4C2
Toll free: 1-800-663-3333
Local 2187 or 3275

December 17, 2003

Dear Patient:

Patient Navigation in Cancer Care Research Project

The BC Cancer Agency, in partnership with the Interior Health Authority, is conducting a research study, *Patient Navigation in Cancer Care*. One important objective of the study is to find out how the navigation services available in the West Kootenay Boundary area help cancer patients to experience better care. In order to do this, the study's researchers need to better understand the experience of patients. We thank you for your interest in this study.

The Cancer Care Navigator is a member of the cancer health care team who works with patients and health professionals to help patients prepare themselves for treatment visits, answer patients' questions about their treatment and care, and provide information about community resources. Your surgeon will refer you to the Cancer Care Navigator, who will be calling you.

Participation in this study is entirely voluntary. If you agree to be in the study, you will take part in three telephone interviews, each lasting 15 to 20 minutes.

I enclose a copy of the Patient Information and Consent Form for your review. A researcher will call you to answer any questions you may have and to see if you consent to take part in the study.

I also include here four coloured sheets, each showing a rating scale, and a medical visit log sheet. If you agree to participate, you will need to use the scale sheets during the interviews. The log sheet will assist you to keep your medical appointments and provide helpful information about your treatments.

If you have any questions, please do not hesitate to call Dr. Joanne Stephen, who is a Co-investigator for this research at (Local 2187) or Dr. Evelyn Ng, the Research Project Coordinator at (Local 3275) using the toll free number shown above. Thank you very much for your time.

Yours sincerely,

Richard Roll, *MSW, MSc*
Director, Sociobehavioural Research Centre



**Patient Navigation in Cancer Care:
A Pilot Study in West Kootenay Boundary
Patient Information and Consent Form**

Principal Investigator:

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- ◆ Joanne Stephen
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Program
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- ◆ Wolfgang Linden, Professor
of Clinical Psychology, UBC
- ◆ Gary Poole, Faculty member
in Health Care and
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UBC

Research Project Coordinator:

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Introduction

The BC Cancer Agency, in partnership with the Interior Health Authority, is conducting research to assess cancer patient support programs and identify areas for improvement. We are inviting you to take part in this study if you have recently been diagnosed with cancer. The Canadian Breast Cancer Foundation, BC Yukon Division, the Canadian Breast Cancer Initiative, and the Canadian Association of Provincial Cancer Agencies are the sponsors of the research.

Purpose of the Study

Patients receiving care for cancer interact with the health care system in multiple sequential steps, receiving care and counselling and undergoing procedures administered by many separate health professionals. The system or professional role intended to improve continuity and coordination of care and patients' psychosocial well-being is called "patient navigation". This system or role of patient navigation is the focus of this research project.

The study aims to identify the events in the navigation system or role serving cancer patients receiving their care in the West Kootenay Boundary region where there is a Cancer Care Navigator. In particular, this study will determine the feasibility of administering 3 interviews to such patients at specific times in the course of their cancer care.

The researchers will use the results of the study to determine the feasibility of a large-scale evaluation of navigation programs in BC, which may, ultimately, help to improve health services for cancer patients.

Who Can Participate

You are eligible for this study if you:

- ◆ Have recently been diagnosed with cancer
- ◆ Have not yet had any treatment to remove the cancer
- ◆ Are older than 19 years of age
- ◆ Are English speaking

Patients seen by surgeons in the West Kootenay Regional Hospital will be contacted to find out if they are interested in the study.

Participation is entirely voluntary, with no effect on further health care.

Study Procedures

Your participation will involve three telephone interviews during which you will be asked to answer a set of questions using a rating scale that will be provided and you will be asked to complete a medical visit log that will be provided.

1. The first interview, within a week, after your consultation with the surgeon
2. The second one, within a week, after your consultation visit to the oncologist
3. The third one, within a week, after your completion of chemotherapy or radiation treatment

Your oncologist will be asked to complete a questionnaire about your consultation visit.

You will be asked to keep a medical visit log to help you keep track of your medical appointments. You will not be asked to return this log.

Each interview will take 15 to 20 minutes. The questions will be about your feelings and thoughts related to the disease and your cancer care. Some of the questions specifically enquire about emotional reactions some cancer patients may have to the stress of having cancer.

Benefits

Your participation will not directly benefit you. However your participation will help the researchers find out how patients access navigation services. This information will be used for planning future research on how to meet patients' needs and may benefit future patients.

Risks

There are no known risks to patients of the study. The only potential risk may be emotional distress that could surface when discussing issues of personal health and experiences of illness.

Confidentiality of Information

Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent. Your identity will not be used in any reports about the study. In records that leave the Investigators' offices you will be identified only by a code number. All information associated with this study will be kept behind locked doors or in secure computer files.

Research records identifying you may be inspected in the presence of the Principal Investigator or his designate by representatives of the funding agencies and the UBC BCCA Research Ethics Board for the purpose of monitoring the research. However, no records that identify you will be allowed to leave the Investigators' offices.

Your Rights

Your participation in this research is entirely voluntary. You may decide not to participate in this study at any time. If you decide to enter the study and withdraw at any time, you will continue to be offered the best available medical care.

Your rights to privacy are protected and guaranteed by the “Freedom on Information and Protection of Privacy Act of British Columbia.” This act lays down safeguards respecting your privacy, and also gives you the right of access and, if need be, correct any errors of personal information. Further details about this act are available on request.

Contacts for Questions

If you have any questions about this project either now or later, you can contact Dr. Joanne Stephen at 1 (800) 663-3333 Ext. 2187 or Dr. Evelyn Ng at 1 (800) 663-3333 Ext. 3275. In addition, if you have any questions concerning your rights as a patient in the study, you may telephone the Information line at the Office of Research Services at the University of British Columbia at (604) 822-8598.

Patient Consent

K	B	0	4			
For Project Use Only						

I understand that participation in this study is entirely voluntary and that I may decide not to participate or I may withdraw from the study at any time and I will continue to be offered the best available medical care. I have also read the patient information and consent form. I understand that I am not waiving any of my legal rights as a result of signing this consent form.

I will receive a signed copy of this consent form for my own records.

Yes I consent to take part in the 3 interviews of the Patient Navigation study

_____ Patient's Signature	_____ Printed Name	_____ Date
_____ Witness' Signature	_____ Printed Name	_____ Date
_____ Investigator's Signature	_____ Printed Name	_____ Date

Thank you very much. Please retain the first four pages for your information; and return this page in the pre-paid envelope.



BC Cancer Agency
CARE & RESEARCH



Interior Health

Scale on Blue Sheet

1 Not at all	2 A little	3 Somewhat	4 Quite a bit	5 A lot
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Appendix 8: Family Physician Questionnaire

Dear Family Physicians:

Timely and comprehensive care for cancer patients is challenging for a number of reasons. We appreciate that family physicians are committed to providing their patients with support, information and guidance during an often lengthy and complex disease course.

The term “Patient Navigation” refers to an approach to improving care for patients with cancer. The purposes of navigation are to increase patient access to services and resources, improve coordination and continuity of care, and help prepare patients and their families by providing information and support.. Patient navigation refers to multi-disciplinary collaboration between physicians and other health care professionals; it also refers to a specific role, usually filled by a specialist nurse, a “Patient Navigator”.

The BC Cancer Agency, in partnership with the Interior Health Authority and the Vancouver Island Health Authority, is conducting a research project, *Patient Navigation in Cancer Care: A Pilot Study*. One objective of the study is to understand the experiences and perspectives of family doctors regarding access and continuity, coordination of care, for cancer patients. Specifically, we want to know how you connect with other health care providers in your community, what navigation functions you provide, and what your perspective and preferences are concerning the patient navigator role.

We are grateful for the time you give to filling out the following survey. It should take not longer than 10 to 15 minutes to complete. The information you provide will ensure that your perspective is included in planning for better care for B.C. cancer patients in the future.

Results of this survey will be held in confidence in keeping with the standards of academic research. No identifying information will be used in the writing of reports that emerge from this survey. The questionnaires will be kept in a locked drawer and destroyed after findings are reported.

Thank you in advance for your input,
Richard Doll
Provincial leader of Rehabilitation

If you have any questions about this research, please contact Valerie Oglov, Research Project Coordinator, Sociobehavioural Research Centre at 604-877-6000 Local 3227 or voglov@bccancer.bc.ca.



**Patient Navigation in Cancer Care: A Pilot Study
Family Physician Questionnaire**

First, we would like to ask some questions about you and your practice.

1. Name _____
2. Age: _____
3. Sex: F M
4. City or town in which you practice _____
5. Years of experience as a family physician: _____ years
6. Practice Type: Please check appropriate categories:

a) <input type="checkbox"/> Solo Practice	b) <input type="checkbox"/> Rural
<input type="checkbox"/> Shared Practice, Standard Clinic	<input type="checkbox"/> Urban
<input type="checkbox"/> Walk-in Clinic	
7. Are you aware of a physician leader for cancer care that you consult with in your area?

<input type="checkbox"/> Yes	<input type="checkbox"/> No
------------------------------	-----------------------------

In this section, we would like to know about the numbers of patients with cancer and your involvement during different phases of the disease course.

8. a) How many cancer patients have you seen within the past 12 months? _____
- b) How many were newly diagnosed? _____
- c) How many are currently receiving treatment? _____
- d) How many are palliative? _____
9. a) Who has communicated the diagnosis of cancer to your patients?

Self, nearly always	Self, most of the time	Specialist, most of the time	Specialist Nearly always

9. b) **Who is the primary physician during active treatment** (eg surgery, radiotherapy, chemotherapy)?

Myself, nearly always	Myself, most of the time	Specialist, most of the time	Specialist nearly always

9. c) **Who provides follow-up care after active treatment?**

Myself, nearly always	Myself, most of the time	Specialist, most of the time	Specialist nearly always

The purpose of the following questions is to obtain an accurate picture of the variety of professionals you communicate with in treating your patients and the range of work you do with patients that could be called navigation work.

10. In providing care to your patients are you likely to communicate with or refer to:

	Never	Occasionally	Often	Always
a) Home care nurses?				
b) Social workers?				
c) Other family physicians/surgeons?				
d) Local oncologist?				
e) Palliative care team/hospice?				
f) Cancer Centre oncologists &/or other Cancer Centre professionals?				
g) Other community health care professionals such as physiotherapists, massage therapists, etc.?				

11. In providing care to your patients, how often would you do the following:

	Never	Occasionally	Often	Always
a) Explain the details of the diagnosis				
b) Provide information about treatment options?				
c) Direct the patient to specific information sources?				
d) Refer the patient to the Cancer Society?				
e) Discuss the emotional impact of cancer?				
f) Discuss care preferences with patients?				
g) Coordinate meetings with family members or other health professionals?				

In this section we would like to know your perceptions and preferences with regard to 1) issues of care, 2) the “navigation” work you currently do, and 3) how you would prefer to interact with a “Patient Navigator” if one were in your area.

12. a) I think there is a need for improved coordination, continuity of care, and access to services for cancer patients

Not at all A little Very much

b) To become more involved in the care of my cancer patients, I would need: (Choose all that apply)

- More time, ie a less busy practice
- Appropriate financial incentive/compensation
- Greater knowledge of cancer
- Enhanced training in oncology care
- More integration with the community cancer team

Greater skill with providing emotional support

Ready access to information and resources

c) I would like to : (Choose all that apply)

Continue practicing as I do, providing some navigation functions.

Share navigation functions with a Cancer Patient Navigator.

Refer my patients to a Cancer Patient Navigator.

Engage more in navigation functions with my patients if appropriately compensated.

12. Is there anything else you would like to say about patient navigation? _____

Thank you very much for taking the time to complete this questionnaire